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Coping, adjustment, and self-concept among siblings of the chronically mentally ill

Marcy Beth Jensen Halvorson
Iowa State University

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Coping, adjustment, and self-concept among siblings
of the chronically mentally ill

by

Marcy Beth Jensen Halvorson

A dissertation submitted to the graduate faculty
in partial fulfillment of the requirements for the degree of
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Major: Psychology (Counseling Psychology)

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Iowa State University

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Major Professor

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For the Major Program

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For the Graduate College

For Peter, may we always continue to dream.

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ABSTRACT

Seventy-four adult siblings of individuals with schizophrenia spectrum disorder were interviewed regarding the effects of coping, social support, premorbid interpersonal closeness, subjective burden, time since onset of the illness, frequency of contact, perceived controllability, and severity of the illness on sibling depression, self-concept, impact on relationships and role functioning. Use of coping was negatively correlated with impact on relationships; social support was negatively correlated with depression and positively correlated with self-concept; frequency of contact and subjective burden were positively correlated with impact on role functioning. There were significant interactions between use of coping and frequency of contact in the prediction of psychological distress and impact on relationships. There were significant interactions between use of coping and perceived severity of the illness in the prediction of depression.

INTRODUCTION

Mental illness can be a devastating and debilitating disease for individuals who suffer from its grasp. Likewise, mental illness can take its toll on the loved ones of those with the illness. Quite a bit of research has been conducted on families of individuals with mental illness. In particular, parents and spouses of the mentally ill have been studied to determine the effects of having a family member with mental illness. However, one family function has been virtually ignored when it comes to understanding how families of the mentally ill adjust to having a member with a mental illness. The family role that has been neglected is the role of siblings.

The siblings bond is a unique one. It makes intuitive sense that brothers and sisters of individuals with mental illness would be strongly affected by the mental illness. Unfortunately, most of the research that has been conducted with siblings of the mentally ill has been methodologically flawed or has been qualitative in nature. One methodological flaw that exist in the current literature concerns recruitment of participants from select sources (e.g., support groups or one hospital setting). Another methodological flaw concerns independence of the study sample. Several of the studies have more than one subject per family, therefore not independent from each other. Other studies conducted on siblings of people with schizophrenia have very low sample sizes. Therefore most of the research on siblings of individuals with schizophrenia or a related illness to date is not very generalizable to the population.

The purpose of this study, then, is to determine the effects of having a brother or sister with a chronic mental illness. In particular, this study examines the impact of various aspects of sibling mental illness on depression, self-concept, other relationships, and functioning in daily roles. It looks specifically at how coping strategies, perceived social support, premorbid interpersonal closeness, subjective burden, time since the onset of the

illness, frequency of contact, perceived controllability of the consequences of events related to the mentally sibling, and severity of the illness affect functioning.

This study can make a contribution to the literature in a number of ways. First, it has a large enough sample size to make generalizations about its findings. Second, it addresses many of the methodological flaws that have been problematic in previous studies (e.g., independence of subjects, various recruitment sources). Third, it examines the impact of various aspects of sibling mental illness that have not been formally assessed previously (e.g., time since the onset of the illness, premorbid interpersonal closeness, perceived controllability). Fourth, it assesses the effects of sibling mental illness on self-concept, including fears for one's own mental health. Fifth, it looks at several ways to buffer the effects of sibling mental illness on one's own functioning. And sixth, several open-ended questions have been asked that can be integrated into future research.

In conclusion, this study assesses the effects of having a sibling with a chronic mental illness on various aspects of functioning. It addresses methodological flaws that have not been successfully addressed in previous research. Unique and new aspects of sibling mental illness are examined in this study. This study also has clinical implications for work with siblings of the mentally ill, including psychoeducational training and therapeutic interventions. These aspects of this study, taken together, have made this an exciting endeavor and potentially an important contribution to the literature.

REVIEW OF RELATED LITERATURE

Mental illness can be very distressing for the individual inflicted with the illness. Illnesses such as schizophrenia and depression can be very painful and discouraging. However, the mentally ill individual is not the only one who suffers. The consequences of mental illness for the families of those who are mentally ill are also highly distressing (Maurin & Boyd, 1990).

This study focused on the families of those with chronic mental illness; the stressors members of the families of the mentally ill faced, how they reacted to the ill member across time, the effect the mental illness has had on the family members' mental health and self-concept, and what could be done to alleviate some of the pain and distress associated with having a mentally ill family member. There has been a significant amount of research conducted on the effects of chronic mental illness on spouses. However, not as much research has been done on the mentally ill individual's family of origin. Knowledge is especially limited with regards to the siblings of the mentally ill. Hatfield (1987a) urges researchers to examine these other relationships, stating that more knowledge is needed in this area. Due to the lack of research conducted on siblings of the mentally ill, this literature review has focused on the effects of mental illness on families in general, and on siblings when the literature has been available. This study has focused on the siblings of those with chronic mental illness. In particular, siblings of individuals with schizophrenia or a related disorder were studied.

Historical Perspectives of Families

Prior to the 1950's, individuals suffering from chronic mental illness were typically placed in an institution (Minkoff, 1978). This inpatient hospitalization tended to be long-term, often lifetime. The families of these institutionalized patients were seldom responsible for their caretaking and well-being. Family members could visit the patients if they wanted to or they could choose to have no contact with the ill member once hospitalization occurred.

Problems arose from this widespread institutionalization. Such problems included overcrowded hospitals, improper care of the patients and lack of funding to pay for the long-term care of mentally ill individuals. These problems, in combination with the development of

major tranquilizers, allowed for a trend that began in 1955, which removed many of these individuals from institutions and placed them in alternate environments. This movement was appropriately termed deinstitutionalization (Minkoff, 1978).

The original goals of deinstitutionalization of the 1950's were apparently met. In 1955 there were approximately 550,000 institutionalized mentally ill patients. This number had been reduced to approximately 100,000 in 1988 (Mechanic, 1989). This deinstitutionalization has had many positive effects, but also has had many consequences for the families of the mentally ill patients that were released. Suddenly, all of these patients had to be placed. Approximately 65% of the patients went to live with a family member (Minkoff, 1978). Minkoff (1978) reported that 35 to 40% of these mentally ill patients returned to live with their spouse and another 35 to 40% returned to their parents. Between 20 and 25% were placed in structured living environments. Goldman (1982) corroborated these findings, stating that 58 to 73% of the mentally ill individuals released during deinstitutionalization returned to live with families, usually the parents.

Some argue that deinstitutionalization was a failure, resulting in homelessness for many of the chronically mentally ill. Indeed, there are currently thousands of mentally ill individuals who are homeless. Dennis (1990) found that between one-fourth to one-third of America's homeless are severely mentally ill. Bachrach (1992) states that many of the disabled mentally ill are unable to gain access to suitable housing on their own, and they have been "evicted" from state hospitals. Thus, they are homeless. In addition, deinstitutionalization was not necessarily followed by the improvement of services for the mentally ill (Borus, 1981; Lamb, 1981; Talbott, 1978). As a result, in the last 15 years, community care for the chronically mentally ill has become a major concern (Mechanic, 1986; President's Commission, 1978).

Currently, psychiatric admissions typically involve a very brief time as an inpatient in the hospital, followed by the patient returning to the community as soon as possible (Goldman, Adams, & Taube, 1983). The family plays an increasingly involved and important part in interactions with mental health professionals and the long-term care of their mentally ill family member (Kreisman & Joy, 1974). In addition to providing the majority of the aftercare of

their mentally ill loved one, families are generally responsible for initiating hospitalization and other treatment (Horwitz, 1978). MacMillan, Crow, Johnson, and Johnston (1986) stated that nearly 60% of first onset schizophrenics were living with relatives when they became ill and the majority of them returned to those relatives' homes after discharge. In light of the increased responsibility of families to care for their chronically mentally ill member, it is important to understand the impact mental illness can have on family members and how they adjust to the illness.

Characteristics of Chronic Mental Illness

Schizophrenia is one of the most devastating of the mental illnesses as well as the least well understood (Andreasen & Black, 1991). Studies of schizophrenia have found prevalence rates to range between .2 to 2.0 % in the general population (American Psychiatric Association, 1994; Kendler, Gruenberg, & Tsuang, 1985). The Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV; American Psychiatric Association, 1994) estimates the lifetime risk of schizophrenia to be 0.5 to 1.0 %. The National Alliance of the Mentally Ill (NAMI, 1989) reported that there are approximately 100,000 new diagnoses of schizophrenia in the United States each year. In addition, in a given year there are approximately 600,000 people in active treatment for schizophrenia (NAMI, 1989).

Genetic factors in the etiology of schizophrenia have been found. Studies have shown prevalence rates of schizophrenia among biological siblings and half siblings to range from 4 to 11 % (Alanen, 1966; Kendler et al., 1985; Stephens, Atkinson, Roth, & Garside, 1975). The risk of developing schizophrenia for monozygotic twins reared together when one of the twins has schizophrenia is 45% (Rowe & Plomin, 1981). Thus, siblings of those with schizophrenia are at an increased risk for the development of schizophrenia. The risk of developing schizophrenia in the general population is quite low, but it is somewhat higher for first degree relatives of those with schizophrenia. Kendler, et al. (1985) found that although siblings of schizophrenics were at an increased risk for the development of non-affective psychotic disorders, they were at no increased risk for the development of affective disorders. Kety, Rosenthal, Wender, Schulsinger, and Jacobsen (1976) found no increased risk for non-schizophrenic diagnoses in biological or adoptive relatives of those with schizophrenia.

Samuels and Chase (1979) found that siblings of those with schizophrenia were functioning at the same level as the population in general. Therefore, it appears that siblings of schizophrenics are not necessarily at an increased risk for non-schizophrenic mental illnesses.

What is schizophrenia and how does it impact the ill individual as well as those around him or her? There are many characteristics of schizophrenia and of those who suffer from it that are important to explore. By definition, chronic mental illnesses like schizophrenia are recurrent and ongoing. Schizophrenia can be cyclical in nature, with cycles of severe symptoms followed by remission of those symptoms. Approximately 30% of patients released from hospitals for the treatment of mental illnesses like schizophrenia return to the hospital during their first year after discharge (Kreisman and Joy, 1974). About one-half of first onset cases of schizophrenia are likely to develop into a chronic and recurrent disabling psychotic illness (Bleuler, 1978). Thus, the severe symptoms of schizophrenia are likely to recur. These cycles of symptoms may correspond to concomitant cycles of hope and disappointment among the families of those with chronic mental illnesses (Lefley, 1989). Families regain hope during the periods of remission and are faced with disappointment when symptoms recur. Even during periods of remission, mild symptoms can, and often do occur.

The clinical symptoms of schizophrenia include both positive and negative symptoms (American Psychiatric Association, 1994). Positive symptoms include delusions, hallucinations, disorganized speech, and disorganized or catatonic behavior. These are characteristics that can be very disturbing for the individual with the illness as well as for the family. These positive symptoms often require crisis intervention or hospitalization. Negative symptoms are not as obvious or florid, but can be just as disturbing. These include flat affect, lack of motivation, isolation, and withdrawal. These negative symptoms tend to be more persistent over time than positive symptoms. Another major characteristics of schizophrenia is social and/or occupational dysfunction. Inappropriate behavior with family and friends or at work can be devastating for the ill individual and the loved ones as well.

Individuals with schizophrenia are typically aware of their own deficiencies and can be very sensitive to how others perceive them. Harris and Bergman (1984) describe four affective responses that individuals with mental illnesses such as schizophrenia may

experience. One possible response is fear, which can come from a variety of sources. Individuals with mental illness may experience fear of leaving the hospital and returning to the community. There may be fear of relearning skills and behaviors that were lost during the episode of the illness. There may also be fear of the demands placed on them to recover and live as normal a life as possible. Another possible affective response in those with schizophrenia is grief over the time and opportunities they have lost during their recent episode. A third response may be despair or hopelessness about the future. These individuals may view their future as a continuous struggle with schizophrenia. Finally, individuals with schizophrenia may experience anger regarding the pain they have experienced and the deprivation they have gone through.

Individuals with schizophrenia generally experience a decrease in their level of functioning, even during remission or recovery. Even during less severe periods and with medications, individuals with schizophrenia usually have an impaired level of functioning. This lowered level of functioning can affect the individuals' productivity, their own self-concept, and their potential to strive to change or improve (Lefley, 1987b).

Strauss, Hafez, Lieberman, and Harding (1985) discuss behaviors of those recovering from an episode of chronic mental illnesses like schizophrenia. They describe the mentally ill individual moving along a nonlinear track which typically consists of three phases. First is what they label a moratorium, or a suspension of action. Not much appears to be happening with the individual. The mentally ill individual may be doing nothing active to recover from his or her episode of schizophrenia. Alternatively, the mentally ill individual may be working on rebuilding his or her skills, but in a subtle way that is not noticeable to those around. The individual is doing this skill rebuilding quietly and without much attention brought to him or her. In either case, there are usually only a few behavioral changes that are noted in the ill individual. The second phase is labeled change points. This phase consists of significant changes in the individual, involving either his or her level of functioning or his or her symptom severity. These changes can move the individual towards exacerbation of the illness or towards improvement. For example, there may be a significant decline in the mentally ill individual's level of functioning. Or there may be significant improvements in his or

her symptom severity. The final phase is called ceilings. Strauss et al. (1985) describe this phase as where the individual with mental illness reaches a plateau where the highest level of functioning attainable has been reached. The individual's level of functioning and symptom severity level off so that there is neither a marked improvement nor a decline. This, of course, will change if the individual has another schizophrenic episode.

Strauss et al. (1985) also discuss a parallel process that families go through in response to a mentally ill family member being discharged from psychiatric hospitalization. At first, the family is in a phase called convalescence. In this phase, loved ones make very few demands on the patient and have low expectations for current functioning. The family provides much support and assistance to the patient to help him or her in his or her recovery. After a couple of months, the family experiences what is called a backlash. This is where the family begins to put pressure on the individual with the mental illness to recover. Often the expectations placed upon the mentally ill person are higher than they were prior to the onset of the illness. These expectations are often unrealistic and lead to disappointment on the part of the family.

Stressors on the Families of the Mentally Ill

A variety of stressors can be the consequence of having a family member with a chronic mental illness. Like mental illness, these stressors tend to be continuous and chronic (Friedrich, 1977; Noh & Turner, 1987). Kreisman and Joy (1974) state that continuous adjustments are required of families of the chronically mentally ill because of the ambiguity of mental illness and the often unpredictable eruptions of deviant behavior. The unrealistic expectations families have regarding the needs of the mentally ill individual and the chronicity of the mental illness can further increase the stress on families (Gantt, Goldstein, & Pinsky, 1989). Families often underestimate what the needs of the ill person will be. They are also likely to underestimate the impact the chronicity of the illness will have on their lives. Thus, they place unrealistic expectations on the mentally ill individual, which can increase the stress for everyone involved. Unfortunately, these stressors are not limited to one domain of the family's life. Chronic mental illness like schizophrenia can cause psychological, physiological

and interpersonal disruption in the lives of the family members of those who are afflicted (Hirschowitz, 1976).

Perhaps the most obvious stress on the families of the chronically mentally ill is financial strain (Kreisman & Joy, 1974; Lefley, 1987a, 1987c, 1987d; Noh & Turner, 1987). This can result from numerous and expensive treatment efforts, which are often only partially successful. Lefley (1989) states that financial strain in the families of the mentally ill come not only from medical bills, but from the patient's economic dependency as well. In most instances, the mentally ill family member is unable to earn his or her own income, therefore relying heavily on his or her family members for financial support. In a study of families of the chronically mentally ill, Kint (1975) found that 61 % of the families in the study reported money being a significant problem for the family of the mentally ill patient.

Another stressor facing the families of the mentally ill is the social stigma that can be attached to those with mental illness. The reactions and attitudes of society to the mentally ill are generally negative (Kreisman & Joy, 1974) and long lasting (Conn & Francell, 1987). The general population does not consider treatment of those with chronic mental illness to be effective and often views the mentally ill as malingerers (Hatfield, 1987b). This stigma often generalizes to the families of the mentally ill (Carlisle, 1984; Hatfield, 1987b; Lefley, 1988; 1989; MacCarthy, 1988). Carlisle (1984) found that many families of the mentally ill have similar attitudes regarding mental illness as the general public. Those of lower socioeconomic status tend to hold more negative attitudes toward mental illness than those of higher socioeconomic status (Hollingshead and Redlich, 1958).

Family members fear rejection once others in their social networks become aware of the mentally ill family member (Carlisle, 1984). Family members may struggle with whom to tell about their mentally ill family member. In addition, families are often blamed for the cause and perpetuation of the mental illness by society as well as professionals (Lefley, 1989). Goffman (1974) discussed the idea that having a mentally ill person in the family can damage the reputation of the family. Therefore, families are often hesitant to discuss the illness in social situations, not sure of who it is safe to tell.

It is apparent from the literature that having a family member with a chronic mental illness like schizophrenia is associated with social stigma. Some researchers have found that this stigma can affect one's own self-concept (Hatfield, 1978; 1987b; Holden & Lewine, 1982; Lefley, 1988). Lefley (1988) states that having a family member with a chronic mental illness can have an impact on well family members' identity. In addition, well family members' self-esteem can become overwhelmed by uncontrollable and insoluble problems caused by the mental illness (Hatfield, 1978; Holden & Lewine, 1982). Some family members of the chronically mentally ill have indicated fears regarding their own mental health and susceptibility to mental illness (Lefley, 1987d; 1988).

The effects of mental illness on the self-concept of family members can be especially dramatic in the case of sibling relationships. Part of the well sibling's identity may be derived from having a deviant sibling (Bank & Kahn, 1982). It can be satisfying for well siblings to know that they are not deviant, like their ill sibling. The well sibling becomes known by the parents as the "normal" and potentially superior child. There is a lot of pressure in being the "normal" sibling. This pressure can take its toll on the well sibling's self-concept. Bank and Kahn (1982) discuss fears well siblings have of becoming like their ill sibling. Some siblings are haunted by these fears. One psychodynamic view is that well siblings often see parts of themselves in their ill sibling; parts that they do not like (Bank & Kahn, 1982). When this happens, well siblings can project this negative part on their ill sibling and disown it for themselves. For example, if their ill sibling is very dependent on other people and the well sibling has some dependent characteristics, he or she may deny that part of himself or herself and instead describe their ill sibling as being "too dependent".

There may also be struggles regarding to whom the well sibling should be loyal, the parents or the ill sibling (Bank & Kahn, 1982). Parents and the ill sibling may have conflicts, and the well sibling may identify with both sides. Some siblings have difficulties separating from their ill sibling (Bank & Kahn, 1982). This can be especially true for siblings close in age or who grew up very enmeshed. These siblings may have difficulties living their own lives, regardless of numerous attempts.

Another stressor that families of the chronically mentally ill face is the changing of roles that occurs when one member becomes ill. Lewis and Zeichner (1960) state that when a member of the family becomes mentally ill, the other family members expect less from the mentally ill person. This can result in role substitution, where one family member takes on a role that the mentally ill individual used to occupy. These roles could include financial roles, personality roles, or interests. The impact of mental illness on the roles of family members is much greater if the mentally ill individual is residing with a family member. Often the responsibilities of caregiving require the primary caregiver to change his or her role in the family as well as make occupational changes (Lefley, 1989). The individual afflicted with the mental illness can no longer fulfill many expectations and the mentally ill individual's well sibling becomes the focus of those expectations (Carlisle, 1984).

Family mental illness can also affect roles outside of the family. In a study of 30 adult siblings of individuals with schizophrenia, Lively, Friedrich, and Buckwalter (1995) found that having a sibling with schizophrenia affected various roles in the well siblings' lives. Sixty-three percent of the sample reported that having a sibling with schizophrenia affected their leisure and interests. This included becoming more involved in the life of the mentally ill sibling as well as having the mental illness interfere with pleasurable activities. Forty-three percent were affected with respect to their work role. Some of these individuals reported being more productive as a result of the mental illness in the family, whereas others reported a decrease in their ability to concentrate because of the mental illness. Thirty-three percent reported that having a schizophrenic sibling affected their role at school, either improving or harming their performance.

Social activities of the families of the chronically mentally ill can also be affected by having a member with a mental illness. Having a family member with a chronic mental illness can place limitations on well members' social activities (Grad & Sainsbury, 1968; Lefley, 1989; Lively et al., 1995). Not only can mental illness in the family affect social life, but it can affect other relationships as well (Lefley, 1989; Lively et al., 1995). Lively et al. (1995) found that siblings of schizophrenics reported that their sibling's illness affected a wide variety of their relationships with others. Eighty-seven percent of the subjects reported that the onset

of illness had a great impact on their relationship with the mentally ill sibling. Some of the siblings reported becoming closer to their ill sibling and others reported distancing themselves from their mentally ill sibling. Seventy-seven percent reported an impact on relationships with parents. Some reported an increase in the closeness of the family, whereas others reported more conflict with parents. Sixty-seven percent reported an impact on relationships with the other well siblings. Again, some reported a positive impact and others reported a negative impact. Seventy-six percent reported an impact on their relationship with their spouse and 53% reported an impact on relationships with other friends. In all of these cases, some reported a positive impact and others reported a negative impact.

One significant source of stress on families of the chronically mentally ill is the odd or eccentric behaviors manifested by the patient. This is especially stressful in the case of schizophrenia. Symptoms of schizophrenia include hallucinations, delusions, uncontrolled outbursts of anger, suspicion, abrupt mood swings, and self-destruction. Behavioral issues are an ongoing concern among mentally ill individuals and the families that care for them (Lefley, 1989). Many researchers have pointed out that families of the mentally ill are continually under severe stress with highly disturbed patients who exhibit irrational, florid and bizarre behaviors (Cook, 1988; Coyne, Kessler, Tal, Turnbull, Wortman, & Greden, 1987; Doll, 1975; Gubman, Tessler, & Willis, 1987; Jacob, Frank, Kupfer, & Carpenter, 1987; Lefley, 1987b). In a study of family caregivers of the chronically mentally ill, Hatfield (1978) reported that positive symptoms were a considerable burden for families.

Negative symptoms of schizophrenia also cause ongoing stress for families of the mentally ill. Negative symptoms of schizophrenia include amotivation, apathy, lack of human relatedness, and other symptoms that involve an absence of normal functions. These have been shown to be as stressful as the positive symptoms for the families (Lefley, 1987b). Some studies have shown these negative symptoms to be more disturbing and burdensome than the positive symptoms of mental illness (Fadden, Bebbington, & Kuipers, 1987; Hooley, Richters, Weintraub, & Neale, 1987; Runions & Prudo, 1983).

Unfortunately, one additional source of stress for families of the chronically mentally ill are mental health service providers. Numerous studies have shown that families of the

mentally ill are often dissatisfied with the services provided by mental health professionals (Bernheim, Lewine, & Beale, 1982; Hatfield, 1978; 1982; 1987b; Holden & Lewine, 1982; Unger & Anthony, 1984). Many families reported that mental health professionals provided inadequate amounts of information regarding the patient's mental illness and how to best cope with it (Carlisle, 1984; Herz, 1984; Holden & Lewine, 1982). Some even reported that the mental health services received by the patient were damaging to the families (Lefley, 1988; 1989). Lefley (1989) cites four sources of damage from professionals. First, mental health professionals can be damaging to the families of the chronically ill by avoiding questions or requests for information that the family presents. Too often the families are not given the information and support they need. Second, the families are often given contradictory messages. For example, some messages imply the family is to blame for the illness in some way and other messages may be that the illness is not their fault. This can result in confusion among family members. Third, mental health professionals may suggest or conduct interventions that alienate the patient's support system. Such interventions can create or increase the distance between the patient and his or her family. Finally, there may be some element of self-fulfilling prophecy involved in the interactions between the family and mental health professionals. The mental health professionals may have preconceived notions as to how the family will behave with regards to their mentally ill member. These notions become expectations that are imposed on the family and thus become fulfilled. One such prophecy might be that the family is not really interested in the treatment of the mentally ill individual. Such responses from the mental health professionals can leave families of the chronically mentally ill under more stress than their situation alone would generate. Hatfield (1987c) suggests that mental health professionals should learn to show respect for families and help them to adapt and cope with what is happening in their lives.

Summary. Having a family member with a chronic mental illness like schizophrenia is an ongoing stress to the families. Due to the chronic nature of the illness, this stress is seldom relieved. In cases where there is relief from the stress, it is usually temporary. There are several types of stress that families face, including financial strain, social stigma, changes in roles and social activities, troublesome behaviors by the patient, and problems dealing with

mental health professionals. All of these stresses can make the impact of having a family member with mental illness more severe.

Emotional Reactions to Mental Illness

Families react to the mental illness of a loved one in a variety of ways. A wide variety of emotional responses can be seen in family members of the mentally ill. Different family members can have very diverse emotional reactions to the mental illness. One member may feel guilt while another feels shame. Emotional reactions can even vary within one member. For example, a sibling may feel both guilt and shame. Finally, these reactions can change dramatically from day to day, or hour to hour. Families often feel anger and resentment towards their mentally ill family member (Holden & Lewine, 1982; Lefley 1987a; 1988). Studies have also shown that families feel guilt over their mentally ill member's illness (Carlisle, 1984; Hatfield, 1981; Holden & Lewine, 1982; Lefley 1985; 1987d; 1988; 1989). This guilt can stem from a variety of sources. Families may feel that they have, in some manner, caused the mental illness in the family member, or didn't recognize it soon enough to get adequate treatment. Guilt can also stem from having hostile feelings toward the mentally ill individual, even though those feelings may be legitimate. They may also feel guilty about their current interactions with the ill member. For example, they may not be as supportive or close to the mentally ill family member as they think they should be.

Some other emotional reactions researchers have found in families of the mentally ill include anxiety over the patient's future (Cook, 1988; Hatfield, 1978; Holden & Lewine, 1982; Horwitz, 1993; Lefley, 1988). Families worry about what will happen to the patient after the parents' death (Lefley, 1987a). Families experience disappointment in the ill member's inability to fulfill their promise in life (Hatfield, 1978; Holden & Lewine, 1982; Lefley, 1988). Families often report fears of violence and unpredictable behaviors (Hatfield, 1978; Lefley, 1988).

Research also indicates that family members of the chronically mentally ill experience a grieving process similar to those who experience a death in the family (Cook, 1988; Hatfield, 1978; 1987b; Holden & Lewine, 1982; Lefley, 1987d; 1988; 1989; MacGregor, 1994; Miller, Dworkin, Ward, & Barone, 1990). The families mourn over the loss of a loved one. However,

this grieving process is different from the grieving process associated with death in one important way. The grieving process for the families of the chronically mentally ill is continuous and recurring. Atkinson (1994) found that parents of schizophrenic children have more ongoing grief than parents of children with head injuries. The psychological, mental and emotional person they once knew and loved is no longer in existence, but the physical person remains. The person that the mentally ill person has become is a constant reminder of the loss they have experienced. Miller et al. (1990) assessed initial grief and ongoing grief regarding a family member with chronic mental illness. They found higher levels of ongoing than initial grief. This grief is terribly difficult for family members to deal with (MacGregor, 1994).

Emotional reactions among siblings. Several researchers have studied the emotional reactions of siblings to their mentally ill family member. In general, these reactions are similar to the emotional reactions of other family members, as described above. Marsh (1992) found that at the onset of the illness, siblings reported feeling much hostility towards the mentally ill person. These siblings often felt that their parents were neglecting their needs. The well siblings reported rejecting the mentally ill sibling and blaming the ill sibling for the strain the mental illness had placed on the family. Newman (1966) also found feelings of guilt, fear, shame, and anger toward the mentally ill sibling. Finally, Titelman (1984; 1991) found that siblings of the mentally ill experienced intense mourning over their sibling's mental illness and fears over their own mental health.

Cognitive Reactions to Mental Illness

When the family member initially becomes ill and goes in for treatment, families believe that the ill individual will return from treatment cured from the mental illness (Lefley, 1987d). They don't understand the long-term impact of the illness on the ill individual's functioning. Once the ill person stabilizes, the families begin to realize that the ill family member's level of functioning is not the same as it was before the onset of the illness. Families then begin searching for explanations for the illness. What were the causes of the illness? Were there warning signs of the illness? Why did it happen to their family member, to their family? What does it mean to have a family member with a chronic mental illness? Often families believe

that their behavior towards the ill member can either create or cure the mental illness (Lefley, 1987d). These ideas often lead to guilt and disappointment.

Taylor (1983) proposes one theory of cognitive adaptation to stressful events that is very relevant to the cognitive reactions families of the chronically mentally ill experience. She argues that the cognitive adjustment process is centered around three themes: meaning, mastery, and self-enhancement. The first theme, the search for meaning in the aversive experience, is really an attempt by the individual to understand the event, in this case the mental illness. As mentioned above, families often ask themselves what caused the illness and why this mental illness has happened to their family. By gaining an understanding of the cause of the illness, family members can begin to understand the significance the illness has for their family. Gaining a sense of meaning of the illness also allows the family members to consider the implications the illness has on their own lives. Taylor (1983) also states that determining meaning for the event is more important in cognitive adjustment than what the actual answer is. That is, the fact that the individual ascribed some meaning to the event is what is important, rather than what meaning they ascribed.

The second theme in Taylor's (1983) cognitive adjustment theory is the importance of gaining a sense of mastery. This theme includes gaining a sense of control over the event and regaining control over one's own life in general. This sense of control is often undermined when threatening events occur. Mastery centers around one's beliefs about his or her ability to manage the event as best he or she can, and prevent the event from recurring. This may be difficult for individuals with a family member who suffers from chronic mental illness like schizophrenia because they do not have control over the illness. However, they may be able to reframe their sense of control by controlling how they respond or react to events surrounding the illness. Alternatively, they may be able to translate control to other aspects of their lives. Reframing their sense of control over the issues related to the mental illness in their family member can increase family member's cognitive adaptation to the illness.

Self-enhancement is the third theme Taylor (1983) proposes. Individuals who are experiencing threatening events often feel a decrease in their self-esteem as a result of the event. This is true even if the event is out of their control. If their self-esteem is lowered due

to the event, they often feel badly about other things in their lives, thus lowering their self-esteem in general. Thus, individuals strive to enhance their self-esteem and return it to the level it was before the event. The most common method of self-enhancement is by downward social comparison (Wills, 1981). Individuals who are undergoing threatening events will compare themselves to others in similar situations. They will generally find some attribute on which they are better off than their comparison person or group. Thus, they feel they are better off than most other people in their situation. Feeling that they are better off than others in their situation enhances their self-esteem in dealing with the situation, and their self-esteem in general. This self-enhancement increases individuals' ability to adapt to the event.

Families of the chronically mentally ill experience several cognitive reactions regarding the illness. Searching for meaning in the experience, attempting to regain mastery over the situation, and enhancing one's self-esteem are effective strategies in the cognitive adaptation or adjustment to threatening circumstances like having a mentally ill family member.

Impact on Health

In the 1930's, Han Selye began studying the reactions to noxious stimuli in rats, and described the General Adaptation Syndrome (GAS) as a non-specific response to noxious stimuli or stress (Selye, 1976). If the noxious stimuli persist, the organism continues through the three phases of Selye's GAS. The first phase is the alarm phase. This is where the body is prepared for immediate action. Second is resistance. Here, the body maintains a lower level of arousal than the alarm phase, but higher than the normal rate. The third phase is exhaustion. In this phase, the body becomes drained of resources, immune functioning becomes impaired and the organism becomes more susceptible to illnesses. Selye (1976), was among the first to suggest that stress, or any outside force that evokes a physiological response, can make individuals more susceptible to illness.

Subsequent research has found that stress in one's life can have an impact on both an individual's physical and psychological health. Continuous and chronic exposure to such stressful situations as those faced by families of the chronically mentally ill have been linked to declining physical and mental health in family members (Kreisman & Joy, 1974; Lefley,

1987a). Grad and Sainsbury (1968) showed that the most common problem reported by families who were living with a mentally ill family member was effects on their own mental health. Likewise, Holden and Lewine (1982) found that emotional responses of the families to their mentally ill family member were associated with both physical and psychological health problems, including insomnia, hypertension, heart attacks, depression, and alcoholism. Lively et al. (1995) found that 67 % of their sample was affected psychologically by their sibling's schizophrenia, and 20 % was affected physically.

Other studies have shown that the impact of stress on physical and psychological health is significant to the extent that the individual perceives the situation as stressful. Noh and Turner (1987) found that having a family member with a mental illness was associated with psychological distress only when the subject perceived the illness as a source of strain. Coyne et al. (1987) studied families of the mentally ill and found that subjective burden was the best predictor of psychological distress.

Families Coping with Mental Illness

Families of the chronically mentally ill can and do find ways to adapt to or cope with their stressful situations. Lazarus, Averill, and Option (1974) have described coping as the efforts an individual makes to master situations of threat, harm, or challenge when the usual strategies they employ are found to be insufficient. How effectively an individual copes with situational demands may moderate the relationship between the stress and the impact it has on the individual's psychological and/or physical health (Wolf, Balson, Morse, Simon, Gaumer, Dralle, & Williams, 1991).

Lazarus (1966) and Lazarus and Folkman (1984) discuss the importance of the cognitive appraisal of a stressful situation in how and to what extent an individual copes with the situation. That is, it is the appraisal of the situation as threatening or harmful that determines coping efforts. For example, one individual may not appraise a certain situation as threatening and therefore not have to invoke coping strategies for that situation. A different individual may appraise the same situation as very threatening and therefore use coping responses. It is the appraisal of the situation that determines to what extent coping strategies are implemented. How an individual appraises a situation is determined by the individual's

personality and environmental circumstances. Lazarus (1966) and Lazarus and Folkman (1984) present three cognitive appraisal processes. First is primary appraisal. This is where the individual judges whether a situational outcome is threatening, beneficial, or irrelevant. If the situation is determined to be threatening, secondary appraisal occurs. This involves developing a response to the threat or taking inventory of the coping options available. The third process is reappraisal. This involves a change in the perception of the situation based on incoming information, which can come from two sources. First, there may be changes in the environmental situation. Second, there may also be changes in internal conditions, such as what the individual thinks about the situation or his or her ability to handle the situation. Appraisal may be a continuous and ongoing process as long as the stress continues. Thus, how the situational demand is appraised determines the extent to which coping strategies are implemented.

Some individuals cope with stressful situations better than others. There are some general characteristics of individuals who are better able to cope with or adapt to stressful events. Mechanic (1974) discussed three components of successful adaptation or coping. First, the individual must have the capabilities and the skills to deal with the demands that are placed upon him or her. These demands may come from the environment and/or social sources. Second, the individual must have adequate motivation to meet these demands. These demands can be associated with intense anxiety and discomfort and it is important that the individual not become overwhelmed by them. Third, the individual must have the capabilities to remain psychologically balanced. He or she must be able to meet his or her external needs, such as day-to-day functioning, rather than focusing primarily on his or her inner emotional needs. If these three components are met, the individual is more likely to successfully adapt to his or her current life stress.

Even for a person who generally copes well, some situational demands can be overwhelming. Wrubel, Benner, and Lazarus (1981) discuss four characteristics of situational demands or stress that can compromise coping or adaptational capabilities. First is the uniqueness of the demand. Uniqueness includes situational demands with which the individual has had no prior experience. He or she has no experience from which to draw

knowledge and skills. Additionally, the culture has no guidelines to follow in coping with the situation. Second, the duration and frequency of the stress can hinder adaptation. Longer and more frequent situational demands can influence the amount of distress that a person experiences. If the demand is very long lasting, the individual may become burnt out. Hopelessness may occur if the duration of the demand seems to be indefinite. Third, the pervasiveness of the demand can affect the person's capabilities to adapt. When the demand encompasses most or all aspects of an individual's life, he or she may feel that there is no refuge from the situational demand. Fourth is ambiguity. The extent to which there is confusion or ambiguity regarding what is happening, what the individual's role in the situation is, and what the likely outcome is, affects adaptational capabilities. For the majority of families of the mentally ill, the mental illness is unique, chronic, pervasive, and ambiguous. Thus, these families are at high risk for their adaptational capabilities being compromised.

Several studies have shown that the perception that one has control over a stressful event can decrease the effects of the stress on health. In a review of the literature, Thompson (1981) described the benefits of several types of control on health outcomes. She made a distinction between behavioral and cognitive control. Behavioral control is the belief that the individual can do something behaviorally to diminish the aversiveness of the stressor. Cognitive control is the belief that the individual can implement a cognitive strategy to reduce the aversiveness of the stressor. In her review of the literature, Thompson (1981) found that behavioral control had no effect on the amount of distress and arousal the stressor produced. Cognitive control over the stressful event, however, reduced the negative impact the stressor had on physical and psychological well-being. Therefore, being able to implement a cognitive strategy to reduce the aversiveness of stressful events is indeed effective in reducing the impact on well-being.

Individuals cope with situational demands in a variety of ways. Most coping strategies can be categorized into one of three types of coping, including problem-focused coping, emotion-focused coping, and less useful coping (Carver, Scheier, & Weintraub, 1989; Lazarus & Folkman, 1984). Problem-focused coping involves implementing strategies to solve the problem or eliminate the source of stress. Emotion-focused coping involves

reducing or managing the emotional distress that occurs as a result of the stress. Less useful coping involves strategies that avoid acknowledging or dealing with the stress and are generally not very effective.

Most individuals will implement some aspects of both problem-focused and emotion-focused coping when faced with stressful events. However, Folkman and Lazarus (1980) discuss circumstances where problem-focused coping or emotion-focused coping may be more beneficial than the other. They have shown that when individuals feel that something can be done to solve the problem or alleviate the stress, problem-focused coping is more effective (Folkman & Lazarus, 1980). That is, if the stress is somehow seen as controllable, problem-focused coping is more likely to alleviate the stress. On the other hand, emotion-focused coping is more effective when individuals feel the stress is uncontrollable and must be endured (Folkman & Lazarus, 1980). So, if the stress is seen as uncontrollable, emotion-focused coping is more likely to alleviate the stress. This has significance for families of individuals with chronic mental illness, since often the stress associated with family mental illness is seen as uncontrollable.

Several studies of the families of the chronically mentally ill have assessed what individuals have done to cope with having a mentally ill family member. Studies have found information sharing has been helpful. Families have found benefits in meeting with other families who are experiencing similar problems (Anderson, Hogarty, & Reiss, 1980). Anderson, Griffin, Rossi, Pagonis, Holder, and Treiber (1986) found that group treatment for families of the mentally ill was effective in increasing feelings of being able to cope with the illness.

MacCarthy, Kuipers, Hurry, Harper, and LeSage (1989) found that using effective coping strategies seemed to increase family member's confidence in dealing with having a family member with a chronic mental illness. Carlisle (1984) interviewed siblings of those with schizophrenia and found several types of coping to be effective in dealing with the illness. Siblings reported implementing a number of coping mechanisms, including focusing on themselves, putting things into perspective, entering psychotherapy, and talking to others. Another strategy invoked in this study was distancing themselves from the situation. Siblings

can and often do escape the direct negative consequences of having a family member with mental illness in the household by moving away (Gubman & Tessler, 1987). Lefley (1987d) describes other coping strategies that have been helpful for families of the mentally ill. These are primarily based on clinical impressions. The strategies include coming to terms with the illness, accepting the illness without losing hope, putting to rest the question of cause, controlling reactions to aversive behavior, educating the clinicians, and taking control of one's own life through advocacy and resource development.

The role of mental health professionals. Researchers have found that the information received by families from mental health professionals is often inadequate (Anderson, et al., 1980; Berkowitz, Kuipers, Eberlein-Fries, & Leff, 1981; Hatfield, 1987c; Main, Gerace, & Camilleri, 1993; Terkelsen, 1987a). They suggest that simply educating the families of the mentally ill about different aspects of the illness can alleviate some of the distress the families face. Several studies have shown that group treatment for families of the mentally ill which educate families on illness-related information and coping strategies have been helpful (Anderson, et al., 1980; Berkowitz, et al., 1981; Leff, Kuipers, Berkowitz, Eberlein-Fries, & Sturgeon, 1982). Anderson et al. (1980) recommend that mental health professionals provide families of those with schizophrenia with current and understandable information regarding etiology, onset, treatment, and prognosis of schizophrenia. They also suggest providing these families with advice regarding how to manage the patient's symptoms at home. Main et al. (1993) state that information sharing between the mental health professionals and the families has assisted the families in preparing for and dealing with situations surrounding the illness. In addition, learning information about mental illness helps the families cope effectively with the stress of having a family member with schizophrenia. Hatfield (1987c) suggests family education, not family therapy, for those who have a family member with a mental illness. Terkelsen (1987a) believes mental health professionals should take on a new role of family consultant in dealing with the families of the mentally ill. He suggests practitioners use the acronym STRIDE (Support and protect the families, Teamwork, Respect other aspects of the families' lives, Information, Develop coping strategies, and Empowerment).

Social Support as a Moderator

Just as effective coping may moderate the relationship between stress and physical and/or psychological health, other psychosocial variables may also serve a protective function. One psychosocial variable that has been shown to moderate this relationship is social support. Kessler, Price, and Wortman (1985) describe social support as the mechanisms through which interpersonal relationships can buffer or protect individuals from the adverse effects of stressful events. Caplan (1974) discusses how close interpersonal relationships can help in times of stress. He discusses three functions of interpersonal relationships, including: 1) helping the individual to mobilize psychological resources and master emotional burdens, 2) sharing tasks and providing supplies or resources, and 3) providing cognitive guidance to increase the effectiveness of handling the situation.

Weiss (1974) describes six different types of social support that may be available across interpersonal relationships. First is guidance. This is described as advice or information and may be of particular importance with regard to families of the chronically mentally ill. Second, Weiss (1974) discusses reliable alliance. He describes this as feeling confident that others are available for tangible assistance. Third is reassurance of worth, or feeling valued by others for one's skills. The fourth type of social support Weiss (1974) describes is the opportunity to provide nurturance. This is the feeling that others count on the individual for their own well-being. It is also described as the sense of being needed. Fifth is attachment, or the emotional closeness and sense of security one feels with others. The final type of social support Weiss (1974) talks about is social integration. This is the sense of belonging to a social network. Weiss (1974) believes that all six types of social support are important in healthy adaptation to stressful events. However, they do not all need to come from the same source, and different events may warrant different amounts of each type.

Cohen and Wills (1985) state that perceived availability of support buffers the adverse effects of life stress. This is often referred to as the "buffering" hypothesis (Cohen & Wills, 1985). Environmental support has been shown to be of central importance in successful coping (Caplan, 1981; Liem & Liem, 1978). There is some empirical evidence that individuals who receive large amounts of social support are less likely to be adversely

affected by stressful life events and therefore less likely to become physically ill (Brown & Harris, 1978; Gore, 1978). This can be applied to families of the chronically mentally ill as well. Individuals who perceive themselves as having adequate social support available may suffer fewer psychological and physical health problems than individuals who do not perceive adequate social support. Potasznik and Nelson (1984) found that as families were more satisfied with the social support they received, they reported less burden from having a family member with a chronic mental illness. Unfortunately, since families of the chronically mentally ill are often isolated socially, they may not have very high levels of perceived social support (Noh & Turner, 1987).

The Family's Response Over Time

The literature suggests that families of the mentally ill respond to their ill family member differently during various stages of the mental illness (Carlisle, 1984; Kreisman & Joy, 1974; Lefley, 1987d; Terkelsen, 1987b). Although few empirical studies have examined the process families go through in response to the mental illness of a family member, there appear to be some consistent trends. Three stages of responses can be extracted from the existing literature. These three stages can generally be described as: 1) the onset of the mental illness, 2) the diagnosis, and 3) acceptance of the mental illness.

Perhaps the most informative study of families' responses to their mentally ill family member was an exploratory study of 20 siblings of the chronically mentally ill (Carlisle, 1984). In this study, Carlisle (1984) interviewed siblings of individuals diagnosed with paranoid schizophrenia or bipolar affective disorder. She asked subjects to describe their reactions to their mentally ill sibling during the onset of the illness, as they were realizing that it was indeed a mental illness, and their current reactions.

Onset. Carlisle (1984) found that the onset of the mental illness was exceptionally difficult for siblings of seriously mentally ill persons. They stated that their mentally ill sibling began exhibiting behavioral changes such as withdrawing from social interactions or acting out inappropriately. One subject reported, "She began withdrawing slowly and reacting unpredictably with hostility" (Carlisle, 1984; p. 24). Other siblings reported their mentally ill sibling having bizarre thoughts or communication patterns. Examples include talking in a way

that doesn't make sense or reporting they have extreme insight into other people's minds. Emotional reactions reported by these siblings included confusion, fear, concern for the ill sibling, denial, anger, frustration, shame and annoyance. About one-half of the subjects responded by interacting more with the ill sibling. Most of the subjects reported trying to talk to their sibling to find out what was wrong or get them to go to the doctor. Some subjects reported changes in their own social relationships because of their ill sibling. They did not want their friends to come over because then they would see their sibling's behaviors. Others reported changes in their family image. For example, one subject reported that the family used to seem secure but now it was fragile. Changes in the well siblings' relationships with their parents were also reported. The most difficult aspect of this stage of mental illness for the siblings was a lack of understanding of what was happening.

Lefley (1987d) corroborated the findings of Carlisle (1984) in stating that most families of the mentally ill have little understanding of what is happening to their family member. They do not understand the symptomatology of the mental illness, the effects of the medications, or the causes of the mental illness. Kreisman and Joy (1974) discuss the onset of mental illness from the family member's perspective. In their discussion they characterize the onset stage as becoming aware of the symptoms of the mental illness and having some anxiety over these symptoms. Anger and passivity are common reactions according to Kreisman and Joy (1974). They also state that minimizing the symptoms, or believing that the symptoms are not as important or severe as they really are, is a frequent reaction among family members of the mentally ill during the onset of the illness.

As can be seen, the onset of mental illness in a family member is an exceptionally difficult time for the other members of the family. This stage is marked by feelings of confusion, anger, and guilt as well as changing relationships within the family. Often the family doesn't realize there is a psychological explanation for the changes in behavior.

Realization. The second stage of the siblings' response to mental illness is the realization that there is indeed something wrong with their sibling. Carlisle (1984) found that for the siblings, the major problems at this stage were the mentally ill person's behavior, coping with this behavior and feelings of guilt and embarrassment surrounding this behavior.

Siblings reported being very worried, resentful, sad, and lonely. One subject stated that her nerves became very bad, that every time the phone rang she feared it would be more bad news about her sibling (Carlisle, 1984; p. 66). Changes in relationships with others were also frequently reported. This was often due to the social stigma associated with mental illness. Several subjects reported being very careful to whom they opened up about their sibling's illness. Many felt afraid to invite friends over to their house because of their sibling. Some subjects also reported changes in the structure of the family. Such changes included how they interacted with their ill sibling, their parents, and other well siblings. In some cases the families became closer as a result of the mental illness in the family; in others the conflict increased. Some of the siblings felt the expectations their parents had of them increased during this stage. Financial strains also became more apparent during this stage. Kreisman and Joy (1974) describe this stage as being when the patient is encouraged to accept the 'sick role.' It is in this stage that the symptoms of the mental illness and disruptive behaviors drive the family and/or the mentally ill individual to seek treatment.

During this stage, family members are still bothered by the behavior of their ill family member and they begin to seek explanations for this behavior through diagnosis. In addition, the emotional and financial strain on the family members becomes more pronounced.

Acceptance. As families enter the third stage and begin to accept the mental illness of their family member, they try to piece together their own lives again. Carlisle (1984) found that the majority of siblings reported feeling sad and concerned over their mentally ill sibling, but many of the feelings of confusion, fear and anger had dissipated. Most of the siblings had no idea what the prognosis of their sibling's illness would be. Some were even able to report some positive outcomes of the illness, including personal development and stronger family relations. The illness had effects on other relationships as well. Some subjects were still careful which friends they disclosed the illness to. Others felt it affected their marriages. One subject stated that she felt torn between her husband and her sibling, that she was always caught between the two (Carlisle, 1984; p. 68). Kreisman and Joy (1974) state that during this stage the patient is generally concerned with improving and trying to return to a functioning adult.

In this final stage, family members of the mentally ill begin accepting the illness. They try to pull their lives back together and the mentally ill individual often tries to do the same.

Terkelsen (1987b) further delineates these stages into ten phases of family response to mental illness over time. Regardless of how many stages or phases are described, it is important to note that families do have different reactions to their mentally ill family member at different periods of the illness. The process they go through and the length of time they spend in each stage may vary depending on circumstances unique to their family. Most studies and reviews, however, have shown that the onset of the illness is the most difficult period for the families (Carlisle, 1984; Kreisman & Joy, 1974; Lefley, 1987d; Terkelsen, 1987b).

Sibling Contact with the Mentally Ill Family Member

Frequency of family contact and the extent to which family members interact with their mentally ill family member may have an impact on their adjustment. Many of the early studies of families of the chronically mentally ill found that the closer the relationship to the mentally ill individual, the greater the perceived threat of the illness on the family members not afflicted with the illness (Schwartz, 1957; Rose, 1959; Mills, 1962; Sakamoto, 1969). Most of these studies, however, were conducted with spouses and parents of the mentally ill rather than with siblings.

Gerace, Camilleri, and Ayres (1993) conducted a study that examined the perspectives of siblings of those with schizophrenia. In their sample, they found three prevailing patterns of involvement in the mentally ill individual's life. The first pattern was what they referred to as collaborative participation. Siblings who fit this pattern tended to be more actively involved in the ill member's life than other groups. They participated in ongoing relationships with the health care professionals. They were also actively involved with other members of the family. These subjects reported being more accepting of the various responses of other family members to the mental illness. They also reported experiencing more hardships and subjective distress over the mental illness than those in the other groups.

The second pattern of contact Gerace et al. (1993) described was called crisis-oriented involvement. Individuals in this group utilized a situation-specific approach to the mental illness. Contacts with the ill family member were generally based around specific

situations that warranted involvement. They dealt with the situation as it arose in a crisis management manner. They did not apply what they had learned in one situation to the next situation. They generally did not have a plan for how to deal or cope with situations until a difficult problem arose that required action. These individuals viewed their role in the family as helping calm the family down during these crises.

The final pattern of involvement described by Gerace et al. (1993) was called the detached approach. These individuals reported they had very little or no involvement with the mentally ill sibling. They reported trying to create a physical and emotional distance between their ill sibling and themselves. These individuals, compared to other groups in this study, actively tried to keep the sibling's mental illness out of their daily life. They reported a diminished sense of responsibility for their ill sibling. These individuals were less involved, and in fact strived actively to remain uninvolved, with their ill sibling. They reported being emotionally unaffected by their sibling's situation. This group also reported an overall lower level of involvement with their family of origin in comparison to other groups in this study. Thus, based on this study, three patterns of illness involvement emerged. The more involved the sibling was in the patient's mental illness, the more distressed he or she was by the illness. Those who distanced themselves physically, did so emotionally as well.

Other studies have shown similar findings. Anderson and Lynch (1984) found an association between the frequency of family contact and the relationship between the ill member and other family members. As contact between the mentally ill individual and the family increased, there were more negative attitudes toward the mentally ill individual. In addition, as contact increased family members reported less perceived social support in coping with having a mentally ill member. Finally, families reported less family cohesiveness or integration when there was frequent contact with the mentally ill member. Other studies have shown that those psychiatric patients with fewer hospitalizations had more family contact than those with more hospitalizations (Myers & Bean, 1968; Rose, 1959). Based on these findings, it may be that it is more difficult for family members to be close to and involved in their ill member's life than it is to be uninvolved. Those who are involved seem to be more distressed about the illness than those who are not.

Predictors of Sibling Involvement. A series of studies conducted by Horwitz (Horwitz, Tessler, Fisher, & Gamache, 1992; Horwitz, 1993; Horwitz, 1994) examined the relationship between the chronically mentally ill and their siblings in a somewhat different manner. Horwitz was interested in the extent to which siblings of the chronically mentally ill provide support to their ill sibling. These studies have shown that the closeness of the personal relationship between siblings is an important predictor of the extent to which well siblings will become involved with their ill sibling (Horwitz et al., 1992). In addition, reciprocity, or the presence of a mutually giving relationship, predicted the amount of assistance reported by the well siblings (Horwitz, 1994). The more reciprocal the relationship was perceived to be by the well sibling, the more assistance he or she was willing to provide to the ill sibling. The number of other roles the well siblings had (e.g., work, marriage, children), and extent of involvement in those roles were also related to the amount of involvement in the ill sibling's life. Those with fewer competing obligations were more involved with and supportive of their ill sibling than those siblings with more competing roles.

Summary. The research on patterns of contact within families of the chronically mentally ill indicate that it is distressing to be highly involved in the mental illness of a family member. Willingness to be involved diminishes with chronicity and over successive hospitalizations. One possible factor in this diminishing involvement may be that family members have a need for a reciprocal relationship with the mentally ill member. If the well members are not receiving any relational benefits from being involved with the ill member, they may be less willing to continue those ties.

Purpose of the Study

This study was designed to assess the effect that having a sibling with schizophrenia or a related illness has on a well sibling's level of depression, self-concept, roles, and relationships. This study was unique in several ways. First, it assessed the effect of having a sibling with schizophrenia or a related illness on one's own self-concept. Second, based on the research conducted by Folkman and Lazarus (1980), it examined the interaction between different types of coping and the controllability of the consequences of a specific stress regarding the sibling's mental illness. Third, it examined the effects of time since the onset of

the mental illness on subject's well-being. Finally, it assessed the role that social support plays in buffering the effects that the additional pain experienced by those who reported a high degree of closeness to their sibling before he or she became ill and subjective burden had on well-being.

Hypotheses

Based on the review of the literature, the following hypotheses were tested.

Hypothesis 1: It was hypothesized that the perceived severity of a sibling's mental illness would have a negative effect on the adjustment of well siblings. Specifically, it was hypothesized that high perceived severity of the sibling's mental illness would be associated with high levels of depression, low self-concept, negative impact on relationships, and negative impact on roles.

Hypothesis 2: It was hypothesized that the frequency of contact with a mentally ill sibling would have a negative effect on the well sibling's adjustment. Specifically, it was hypothesized that high frequency of contact with the mentally ill sibling would be associated with high levels of depression, low self-concept, negative impact on relationships, and negative impact on roles.

Hypothesis 3: It was hypothesized that the effects of having a mentally ill sibling would change over time. Specifically, it was hypothesized that less time since the onset of the mental illness would be associated with high levels of depression, low self-concept, negative impact on relationships, and negative impact on roles.

Hypothesis 4: It was hypothesized that the perception of uncontrollability in situations related to a sibling's mental illness would have a negative impact on adjustment in well siblings. In addition, based on the findings of Folkman and Lazarus (1980), it was hypothesized that the use of emotion-focused coping behaviors would buffer this effect. Specifically, it was hypothesized that there would be an interaction between the use of emotion-focused coping behaviors and controllability of the consequences of an event related to the mentally ill sibling in the prediction of depression, self-concept, impact on relationships, and impact on roles. It was predicted that the association between uncontrollable events and

negative outcomes would be weaker when much emotion-focused coping was used than when little emotion-focused coping was used.

Hypothesis 5: It was hypothesized that there would be an interaction between the use of problem-focused coping behaviors and controllability of the consequences of an event related to the mentally ill sibling in the prediction of depression, self-concept, impact on relationships, and impact on roles. Based on the findings of Folkman and Lazarus (1980), it was predicted that problem-focused coping would buffer the effects of controllable events. That is, the association between controllable stressors and negative outcomes would be weaker when problem-focused coping was used often than when it was used infrequently.

Hypothesis 6: It was hypothesized that premorbid interpersonal closeness with the ill sibling would have a negative effect on the well sibling's adjustment. In addition, it was hypothesized that the perception of social support would buffer this impact. Specifically, it was hypothesized that there would be an interaction between interpersonal closeness with the mentally ill sibling prior to the onset of the illness and perceived social support in the prediction of depression, self-concept, impact on relationships, and impact on roles. It was predicted that the association between premorbid interpersonal closeness and depression, self-concept, impact on relationships, and impact on roles would be stronger when perceived social support was low than when perceived social support was high.

Hypothesis 7: It was hypothesized that subjective burden of the mentally ill sibling would have a negative impact on the well sibling's adjustment. In addition, it was hypothesized that the perception of social support would buffer this impact. Specifically, it was hypothesized that there would be an interaction between subjective burden of the mentally ill sibling and perceived social support in the prediction of depression, self-concept, impact on relationships, and impact on roles. It was predicted that the association between subjective burden and depression, self-concept, impact on relationships, and impact on roles would be stronger when perceived social support was low than when perceived social support was high.

METHOD

Participants

Seventy-four adult siblings (males = 27, females = 47) of individuals with chronic schizophrenia, schizotypal, or schizoaffective disorder (as diagnosed by the DSM-IV; American Psychiatric Association, 1994) were recruited for participation in this study. Study participants were recruited from a number of sources. Recruitment sources and the percent of the study participants from each source are shown in Table 1. Appropriate patients in local

Table 1. Recruitment Sources of Study Participants (N = 74)

Variable	N	%
Alliance for the Mentally Ill	29	39
Veteran's Affairs Medical Center	19	26
Broadlawns Medical Center	10	14
Iowa Lutheran Hospital	1	1
River Valley Residential Center	3	4
Westminster House	3	4
Rainbow Center	2	3
Eyerly Ball Mental Health Center	2	3
Other	5	7

hospitals, mental health centers, and residential facilities were approached and asked if they would be willing to provide the names, addresses, phone numbers, and ages of their siblings for possible participation in this study. Letters for patients and residents are shown in Appendix A. Members of local support groups were asked if they knew of someone who met the criteria for participation in this study. If so, they were asked to provide names, addresses,

phone numbers, and ages of the siblings of the mentally ill individual. Letters to the support group members are shown in Appendix A. Corroborator information regarding diagnosis and other aspects of the mental illness was obtained for 38 of the participants.

Several methods were used to determine the number of subjects needed for this study (Cohen, 1977). The general heuristic used to determine the number of cases required for regression analyses is 10 subjects per predictor variable in a given equation. In this study, the largest regression equation had five variables. Therefore, 50 participants would suffice. Additionally, a power analysis was conducted and indicated that 90 participants would be needed to detect a moderate effect size. Based on these numbers, a goal of 70 - 90 participants was set. Due to difficulty in recruiting participants and financial constraints, 74 participants was considered adequate.

Sibling Diagnosis

Every care was taken during recruitment to ensure that the ill sibling met the criteria for a schizophrenia related mental illness. For those individuals who were recruited through hospital patients and residential care facility residents, only individuals who met the study criteria were approached regarding participation in this study. That is, the staff at the facility had access to an accurate diagnosis and only approached patients or residents with an appropriate diagnosis. Therefore, all of those participants had a sibling with an appropriate diagnosis. The participant's report of diagnosis was used unless there was uncertainty, in which case corroborator information or medical records were used. For participants recruited through support groups, medical records were not available. For most of these participants, participant report of the diagnosis was used. If participants were uncertain of the diagnosis, corroborator diagnosis was used. Out of the entire sample, the participant's report of diagnosis was used in all but five cases. In those five instances, the study participant was unable to provide an accurate diagnosis. Therefore, either corroborating diagnostic information from a parent or other close relative of the ill sibling or diagnostic information from the ill sibling's medical record was used. Based on a combination of this information, all of the ill siblings met the criteria for this study. Table 2 shows diagnoses that were used for the ill siblings.

Table 2. Diagnoses of Ill Siblings (N = 74)

Diagnosis	N	%
Schizophrenia	60	81
Schizoaffective Disorder	11	15
Schizophreniform Disorder	1	1
Schizotypal Personality Disorder	1	1
Psychotic Disorder, not otherwise specified	1	1

Procedure

Once names, addresses, phone numbers, and ages of the potential participants were collected, the sibling closest in age to the index patient was mailed a letter of introduction to the study. Letters for potential participants recruited from patients, residents of group homes, and support group members are shown in Appendix A. This letter informed potential participants of how their name was obtained and the nature of the study. All patients and participants were assured that their participation would have no effect on the treatment of the ill person and that participation would be strictly voluntary. They were also informed that they would soon be contacted by telephone and asked to participate in the study. Potential participants were then contacted by telephone, given information regarding the study (shown in Appendix B), and if consent for participation was granted, an interview was scheduled regarding their experiences of having a sibling with chronic mental illness. Participation in the telephone interview was considered consent. It was clearly stated in the letter and on the telephone that if at any time they wished to have their name removed from the list or decided to withdraw from participation in the study, they could do so without penalty to themselves or their ill family member. Telephone interviews were conducted by the primary investigator and lasted approximately 30 - 45 minutes. Research participants were offered a summary of results upon completion of the study.

Research participants were asked if there was a parent or other relative available that might have more specific information regarding diagnosis, age of onset, and other aspects of the mental illness. If the participant felt comfortable providing a name and phone number of a corroborator, the corroborator was then contacted for a five minute telephone interview.

Eighty-four potential participants were mailed letters of introduction to this study. Of these, 74 agreed to participate (88%). Of the ten that did not participate, one subject felt his or her sibling was inappropriate for the study (1%), one subject was unreachable (1%), two reported that the mentally ill sibling was deceased (2%), and six reported not being interested in participating (7%). Therefore, of the potential participants who were contacted and appropriate for participation for this study, 93% participated. Thirty-eight participants provided corroborator information. Of those 38 potential corroborators, 100% agreed to participate in the five minute interview.

Inclusion criteria for this study were that 1) the study participant must be at least 18 years of age at the time of the interview, 2) the study participant must have a living sibling with a schizophrenia related chronic mental illness (including schizophrenia, schizoaffective, schizophreniform, schizotypal personality, or another disorder with psychotic features).

Predictor Variables

The effects of nine predictor variables were investigated in this study. They were 1) the use of problem-focused coping, 2) the use of emotion-focused coping, 3) perceived social support, 4) premorbid interpersonal closeness with the mentally ill individual, 5) subjective burden imposed by the mentally ill individual, 6) time since onset of the illness, 7) frequency of contact with the mentally ill sibling, 8) perceived controllability of the consequences of events related to the mentally ill sibling, and 9) perceived severity of the sibling's illness.

Outcome Variables

The outcome variables for this study were 1) participant's level of depression, 2) participant's self-concept, 3) impact of the sibling's illness on the participant's relationships with other people, 4) and impact of the sibling's illness on the functioning of the participant in his or her daily roles.

Control Variables

Control variables included 1) demographic characteristics of the study participant and the mentally ill sibling and 2) the number of stressful life events in the last year that were unrelated to the mentally ill sibling.

Measures

Subjects were administered a semi-structured interview over the telephone. This interview consisted of several published instruments and some additional questions. Listed below are the variables that were assessed and the instruments used to assess them. The entire questionnaire is shown in Appendix C. The corroborator questionnaire is shown in Appendix D. Descriptive statistics and alpha coefficients for the predictor and outcome measures and stressful life events are shown in Table 3.

Demographics. Demographic variables were assessed for both the study participant and the mentally ill individual. Demographic variables for the study participant included source of recruitment, age, gender, marital status, education, employment status, income, number of siblings, birth order, and blood relation to the ill sibling. Demographic variables for the mentally ill individual included age, gender, marital status, education, employment status, birth order, number of children, disability status, number of psychiatric hospitalizations, most recent psychiatric hospitalization, current living situation, whether or not the ill sibling was homeless, and distance in miles from the ill sibling.

Validity for participant report of sibling information. Corroborator data was obtained for 38 participants. This information was obtained from a parent or other relative who had accurate information regarding the mentally ill sibling's diagnosis. Information obtained included diagnosis, age of onset, information regarding hospitalizations, disability status, and living conditions. Corroborators were also asked their impressions of how close the mentally ill sibling and the participant were as children. There was 74% agreement between corroborator and participant reports of diagnoses, KAPPA = .48. Likewise, the correlations between the participant and corroborator reports of other information regarding the ill sibling were very high (see Table 4). This corroborator data provides validity to this study and the extent to which the information provided by the participants was accurate.

Table 3. Descriptive Statistics for Predictor, Outcome, and Control Variables (N = 74)

Variable	<u>M</u>	<u>SD</u>	Min	Max	Alpha
Predictor variables					
Problem-focused coping	46.55	10.75	24	78	.62
Emotion-focused coping	27.82	5.84	15	44	.45
Social support	17.27	2.77	5	20	.87
Closeness	14.62	3.46	6	24	.83
Subjective burden	34.64	8.19	19	54	.88
Time since onset	18.86	10.99	2	50	-----
Frequency of contact	8.04	2.89	2	14	.71
Controllability	22.56	6.33	9	38	.67
Severity	14.61	2.35	9	18	.61
Outcome variables					
Depression	30.66	10.42	20	66	.93
Self-concept	60.92	8.36	38	75	.88
Impact on relationships	18.59	3.51	10	29	.66
Impact on roles	9.27	1.38	4	13	.48
Control variables					
Stressful life events	3.76	2.72	0	11	-----

Table 4. Correlations Between Participant and Corroborator Report of Demographic Information of the Ill Sibling (N = 38)

Variable	r
Current age of the ill sibling	1.00***
Age of first psychiatric diagnosis	.79***
Age of first psychiatric treatment	.68***
Age of first psychiatric hospitalization	.93***
Age first noticed something was wrong	.65***
Receiving disability	.52**
Length of time receiving disability	.68***
Ever been homeless	.42**
Number of psychiatric hospitalizations	.49**
Most recent psychiatric hospitalization	.81***
Current living situation	.71***

* $p < .05$. ** $p < .01$. *** $p < .001$.

Coping. Coping was measured with selected items of the COPE (Carver, et al., 1989). The COPE is a 53-item multidimensional coping inventory that assesses three broad dimensions of coping that people use in responding to stressful situations, including problem-focused, emotion-focused, and less-useful coping. Only the two dimensions of problem-focused and emotion-focused coping were assessed in the current study. These two dimensions are further delineated into 10 specific sub-scales. For this study, problem-focused and emotion-focused coping related to a specific situation was assessed. Subjects were asked what the most difficult problem has been in dealing with their mentally ill sibling. They were asked to respond to the COPE items with reference to how they coped with that

specific problem. Each item on the COPE was rated on a four-point scale, ranging from "1 = I didn't do this at all" to "4 = I did this a lot".

The COPE has high internal consistency. Cronbach's alphas for the COPE scales range from .45 to .92, with only one scale falling below .60 (Carver, et al., 1989). Test-retest reliability of the COPE is also high. Test-retest correlations range from .42 to .89 across six-week and eight-week intervals (Carver, et al., 1989). The COPE has good convergent validity. Carver, et al. (1989) found that coping strategies that are thought to be functional were related to conceptually related personality factors. The active coping and planning scales of the COPE were positively correlated with optimism, control, self-esteem, hardiness, and Type A personality (Carver, et al., 1989). In addition, the positive reinterpretation and growth scale of the COPE was positively correlated with optimism, control, self-esteem, and hardiness. Discriminant validity was also found (Carver, et al., 1989). The denial scale of the COPE was positively correlated with trait anxiety and negatively correlated with optimism, control, self-esteem, and hardiness. In sum, the COPE has been found to be a reliable and valid instrument to measure coping strategies.

Problem-focused coping consists of five scales (active coping, planning, suppression of competing activities, restraint coping, and seeking of instrumental social support). The item that had the highest factor loading for each scale was selected for inclusion in this study. The total problem-focused coping score was the sum of the five items. These five items had a Cronbach's alpha of .62. A sample problem-focused coping item is, "I took additional action to try to get rid of the problem".

Emotion-focused coping consists of five scales (seeking of emotional social support, positive reinterpretation, acceptance, denial, and turning to religion). The item that had the highest factor loading for each scale was selected for inclusion in this study. Two of these items were not highly correlated with the other three and were therefore deleted from the scale. The total emotion-focused coping score was the sum of the three items. These three items had a Cronbach's alpha of .45. A sample emotion-focused coping item is, "I talked to someone about how I felt".

Social support. Social support was measured using selected items from the Social Provisions Scale (SPS; Cutrona & Russell, 1987). This is a 24-item measure that assesses six types of social support. These six subscales are 1) Reliable alliance, or the confidence that others are available to provide tangible aid, 2) Attachment, or emotional closeness and security, 3) Guidance, or advice or information, 4) Nurturance, or the sense that one is needed by others, 5) Social Integration, or belonging, and 6) Reassurance of Worth, or value by others.

The subscales of the SPS have been shown to be reliable across several studies (Constable & Russell, 1986; Russell, Altmaier, & Van Velzen, 1987; Cutrona & Russell, 1987). The subscale coefficient alphas from these combined studies ranged from .65 to .76, with an overall Social Provision Score coefficient alpha of .92 (Cutrona & Russell, 1987). The SPS has good convergent and discriminant validity (Cutrona & Russell, 1987). Cutrona and Russell (1987) correlated the SPS with several other measures of social support; including the Social Support Questionnaire (Sarason, Levine, Basham, & Sarason, 1983), the Index of Socially Supportive Behaviors (Barrera, Sandler, & Ramsay, 1981), and attitudes toward the use of social support (Eckenrode, 1983). Correlations ranged from .35 to .46 (p 's < .001). Correlations between the SPS and other relevant measures were computed, including the Marlowe-Crowne Social Desirability Inventory, the Beck Depression Inventory, the introversion-extroversion and neuroticism scales of the Eysenck Personality Inventory, and number of stressful life events. A hierarchical multiple regression analysis showed that scores on the SPS were significantly related to the other support measures when the other relevant measures were controlled for.

For this study, the subscale assessing nurturance was not included because it measures the giving of social support. For this study, I was primarily interested in the perceived social support available to the subject, and therefore excluded nurturance. The item from each of the remaining 5 subscales with the highest item-total correlation was selected for use in this study. Responses were made on a four-point scale, ranging from "1 = strongly agree" to "4 = strongly disagree". The total Social Provisions score was the sum of all five items (after reverse scoring of appropriate items). These five items had a Cronbach's

alpha of .87. A sample perceived social support item is, "There are people I can depend on to help me if I really need it".

Interpersonal closeness. Premorbid interpersonal closeness with the mentally sibling was measured with questions designed for this study. Subjects were asked six questions regarding their premorbid interpersonal closeness to the ill sibling. Three questions pertained to their closeness as children, and three related questions pertained to their closeness during the two years prior to the onset of the illness. Responses were made on a four-point scale, ranging from "1 = strongly agree" to "4 = strongly disagree". The total interpersonal closeness score was the sum of all six items. These six items had a Cronbach's alpha of .83. A sample interpersonal closeness item is, "As children, I felt very close to my ill sibling".

Burden. Subjective burden was assessed using nineteen questions developed by Lively, et al. (1995) in a study of siblings of persons with schizophrenia. No psychometric information was available for this measure. Subjects are asked to what extent each of the 19 items have been a problem to them or their family. Items are scored on a scale from "1 = not a problem" to "3 = very much a problem". The total subjective burden score was the sum of all nineteen items. In the current study, these nineteen items had a Cronbach's alpha of .88. A sample subjective burden item is, "Offensive personal hygiene or grooming".

Time since onset. Time since the onset of the sibling's mental illness was measured by subtracting the ill sibling's age at first diagnosis from the ill sibling's current age.

Frequency of contact. Frequency of contact with the mentally ill sibling was assessed using two items. These items asked about the frequency of in-person contact and telephone contact. The total frequency of contact score was the sum of the two items. These two items had a Cronbach's alpha of .71.

Controllability. To assess the controllability of stressful events, subjects were asked to report the most difficult or stressful problem they have faced regarding their sibling's mental illness. Controllability over the consequences of the event was then rated by the subject from three perspectives including 1) controllability by the subject, 2) controllability by the ill sibling, and 3) controllability by others. This scale consisted of nine items adapted from the Stress Dimension Scale (SDS; Swanson, 1990). Cronbach's alphas for the entire SDS

range from .77 to .95 (Cutrona & Suhr, 1992). The total controllability score for this study was the sum of the nine items. Each item on this scale was rated on a five-point scale, ranging from "1 = no control" to "4 = very much control". In an adult sample of Type II diabetics, Swanson-Hyland (1996) found a mean item controllability score of 3.11. The mean item controllability score for the sample in the current study was 2.51, somewhat less than that for individuals with chronic physical illness. The nine items for controllability had a Cronbach's alpha of .67. A sample perceived controllability item is, "How much control did you have over the outcome of this situation?".

Severity. Perceived severity of the mental illness was measured with questions designed for this study. Subjects were asked four questions regarding their perceptions of the severity of their sibling's illness. Two of the items on this scale were rated on a five-point scale, ranging from "1 = not at all severe" to "4 = extremely severe". The other two items were rated on a four-point scale, ranging from "1 = very unlikely" to "4 = very likely". The total perceived severity score was the sum of all four items. These four items had a Cronbach's alpha of .61. Sample perceived severity items are, "To what extent has {sibling's} illness disrupted his or her own life?", and "How likely is it that {sibling's} condition will improve significantly?".

Depression. Depression was measured with the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). This scale is a 20-item scale designed to measure depressive symptomatology in the general population. The CES-D has been found to have very high internal consistency (Radloff, 1977), with Cronbach's alpha ranging from .84 to .90. Radloff (1977) reported eight-week test-retest reliability coefficients ranging from .51 to .67, and 12-month test-retest reliability coefficients ranging from .32 to .54. With regard to validity, Radloff (1977) found the CES-D to discriminate well between psychiatric inpatients and samples from the general population. The CES-D discriminated moderately among levels of severity within the inpatients. Weissman, Prusoff, and Newberry (1975) compared the CES-D with the Hamilton Rating Scale for Depression and the Raskin Rating scale upon admission for inpatient psychiatric treatment (correlations ranging from .44 to .54) and after four weeks of treatment (correlations ranging from .69 to .75).

For each item on the CES-D, subjects were asked, "How often in the past week did you...?" Sample items include "...I felt that I could not shake off the blues even with help from my family and friends", or "I felt lonely". Each item was measured on a four-point scale, ranging from "1 = rarely or none of the time" to "4 = most of the time". The total depression score was the sum of all twenty items. These twenty items had a Cronbach's alpha of .93.

Self-concept. The subject's self-concept was measured in two ways. One aspect of self-concept that was measured was global self-concept. This was assessed with the Rosenberg Self-Esteem Scale (RSE; Rosenberg, 1965). This is a 10-item scale consisting of statements about the self. It is scored on a four-point response scale with responses ranging from "1 = strongly agree" to "4 = strongly disagree". A sample self-concept item is, "At times I think I am no good at all".

In the original normative sample, the RSE scale had high internal consistency, with Cronbach's alpha of .77 (Rosenberg, 1965). Subsequent studies have also found the RSE scale to have high internal consistency, with Cronbach's alphas ranging from .72 to .87 (Byrne & Shavelson, 1986; Dobson, Goudy, Keith, & Powers, 1979; Orme, Reis, & Herz, 1986; Schmitt & Bedeian, 1982; Ward, 1977). The RSE scale has good test-retest reliability, ranging from .63 to .85 (Byrne, 1983; Silber & Tippet, 1965). The RSE scale has also been found to have good convergent and discriminant validity. Byrne (1983) correlated the RSE scale with Coopersmith's Self-Esteem Inventory (Coopersmith, 1981) at two points in time and found the convergent validity coefficients to range from .58 to .60. Byrne and Shavelson (1986) found convergent validity coefficients of .79 and .64 when correlating the RSE with the General Self Esteem scale of the Self-Description Questionnaire III and the Self-Concept subscale of the Affective Perception Inventory, respectively. Other studies have corroborated these findings. Byrne (1983) intercorrelated the RSE with Coopersmith's School-Academic subscale and Brookover's Self-Concept of Ability scale (Brookover, 1962; Coopersmith, 1981) at two points in time and found the validity coefficients to range from .35 to .46. Byrne and Shavelson (1986) found that the RSE did not correlate highly with general academic self-concept, mathematics self-concept, and English self-concept. This suggests

that the RSE measures general self-esteem. The total global self-concept score was the sum of the ten RSE items. These ten items had a Cronbach's alpha of .90.

The second way that self-concept was measured was by assessing the specific impact that having a sibling with a chronic mental illness had on the subject's self-concept. Nine items designed for this study were used to assess this impact. Several of these questions were adapted from the RSE. These questions were also scored on a four-point response scale with responses ranging from "1 = strongly agree" to "4 = strongly disagree". A sample item is, "Since {sibling} became ill, I view myself more negatively". The total impact on self-concept score was the sum of the nine items. These nine items had a Cronbach's alpha of .68.

The two self-concept scales were highly correlated, $r(72) = .57$, $p < .001$, and therefore were combined to form an overall measure of self-concept. The total self-concept score was the sum of these nineteen items. These nineteen items had a Cronbach's alpha of .88.

Impact on relationships. Lively et al. (1995) assessed the impact of having a sibling with schizophrenia on six types of relationships (with the ill sibling, other well siblings, parents, spouse, children, and friends). The questions Lively et al. (1995) used were slightly modified for use in this study. No psychometric information was available for this measure. Participants were asked if the ill sibling's illness has had an impact on various relationships, and if so whether that impact has been mostly positive or negative. They then classified the impact as somewhat or very positive/negative. Neither positive nor negative impact was also a response option. These questions were then scored on a five-point response scale with responses ranging from "1 = very positive impact" to "5 = very negative impact". The total impact on relationships score was the sum of the six items. These six items had a Cronbach's alpha of .66. A sample impact on relationships item is, "Has {sibling's} illness had an impact on your relationship with your parents? If so, has that impact been mostly positive or negative? Would you say somewhat positive/negative or very positive/negative?".

Impact on roles. Lively et al. (1995) assessed the impact of having a sibling with schizophrenia on four different life roles (work, school, finances, and leisure). The questions

Lively et al. (1995) used were slightly modified for use in this study. No psychometric information was available for this measure. The item measuring impact on finances was not highly correlated with the other items and was therefore not included in the scale. The total impact on roles score was the sum of the remaining three items. These three items had a Cronbach's alpha internal consistency of .48. A sample impact on roles item is, "Has {sibling's} illness had an impact on your performance at work? If so, has that impact been mostly positive or negative? Would you say somewhat positive/negative or very positive/negative?".

Life events. Stressful life events were measured by using selected items from the Psychiatric Epidemiology Research Interview (PERI) Life Events Scale (Dohrenwend, Krasnoff, Askenasy, & Dohrenwend, 1978). This is a 97-item measure that assesses stressful life events that have recently occurred. The PERI has been widely used in studies of stress and adjustment, and shows predicted correlations between number of events and a wide range of outcome variables (Dohrenwend, et al., 1978). For this study, irrelevant items, overly personal items, and items assessing positive events were eliminated, leaving a total of twenty five items. Only events unrelated to the ill sibling were assessed. Subjects responded "Yes" or "No" as to whether each life event had happened to them within the last year. The total stressful life events score was the sum of all twenty five items. A sample life event item is, "Have marital problems".

Open-ended questions. Seven open-ended questions were asked to provide more qualitative information from the subjects. Open-ended questions assessed in what ways having a sibling with schizophrenia has affected the subjects' self-concept, how subjects have coped with this stressor, what has been the hardest part of having a sibling with schizophrenia, and how the relationship between the subject and the ill sibling has changed since the onset of the illness. Responses the open-ended questions and subsequent discussion are in Appendix E.

RESULTS

Demographics

The demographic characteristics of the study participants and the mentally ill siblings are shown in Tables 5 and 6, respectively. The mean age of the study participants was 43.61 ($SD = 12.71$) and the mean age of the mentally ill siblings was 43.35 ($SD = 11.82$). Fifty percent of the study participants were older than their mentally ill siblings and 50% were younger. Ninety-two percent of the mentally ill siblings were biological siblings, 1% (one sibling) was a fraternal twin. Of the study participants, 58% were married, whereas 15% of the ill siblings were married. There were more females than males among the study participants (64% and 36%, respectively), but more males than females were ill siblings (61% and 39%, respectively). This is representative of the schizophrenic population (American Psychiatric Association, 1994). Eighty-two percent of the study participants had some education beyond high school, 47% were college educated, and 15% had education beyond a college degree. In comparison, 57% of the ill siblings had some education beyond high school, 20% were college educated, and 5% had received some education beyond college. Many of the study participants lived within close proximity of their ill sibling: 10% lived within two miles and 25% lived within 15 miles of their ill sibling. Others lived very far from their ill sibling: 25% lived over 600 miles and 11% lived over 1000 miles from their ill sibling.

Some additional characteristics of the mentally ill siblings are noteworthy. Eighty-four percent of the mentally ill siblings were receiving disability payments for their mental illness. They had received disability payments for an average of 4.29 years ($SD = 1.09$). The mean age for first diagnosis was 24.51 years ($SD = 7.93$). Eighty-seven percent of the mentally ill siblings had been hospitalized more than three times for psychiatric problems; 61% had been hospitalized more than six times, and 32% had been hospitalized more than ten times for psychiatric problems. Only 1% of the mentally ill siblings had never had a psychiatric hospitalization. Forty-one percent of the mentally ill siblings were hospitalized within the past

Table 5. Demographic Characteristics of Study Participants (N = 74)

Variable	%	<u>M</u>	<u>SD</u>	Min	Max
Age		43.61	12.71	19	75
Gender					
Male	36				
Female	64				
Marital status					
Never been married	19				
Engaged	1				
Married	58				
Separated	1				
Divorced	15				
Widowed	5				
Education					
Some high school	1				
High school graduate	16				
Some college, junior college, or trade school	35				
College graduate	32				
Beyond college graduate	15				
Employment status					
Full-time	54				
Part-time	14				
Not employed	32				

Table 5. (continued)

Variable	%	<u>M</u>	<u>SD</u>	Min	Max
Household income					
\$0-\$15,000	14				
\$15,001-\$30,000	18				
\$30,001-\$45,000	22				
\$45,001-\$60,000	24				
\$60,001-\$75,000	12				
Over \$75,000	10				
Number of siblings		3.27	2.50	1	16
Birth order		2.65	1.84	1	9
Blood relation to ill sibling					
Biological sibling	92				
Fraternal twin	1				
Half-sibling	3				
Adopted sibling	4				

Table 6. Demographic Characteristics of Ill Siblings (N = 74)

Variable	%	<u>M</u>	<u>SD</u>	Min	Max
Age		43.35	11.82	18	78
Gender					
Male	61				
Female	39				
Marital status					
Never been married	60				
Engaged	1				
Married	15				
Separated	3				
Divorced	19				
Widowed	3				
Education					
Eighth grade or less	1				
Some high school	7				
High school graduate	35				
Some college, junior college, or trade school	37				
College graduate	15				
Beyond college graduate	5				
Employment status					
Full-time	7				
Part-time	18				
Not employed	74				
Don't know	1				

Table 6. (continued)

Variable	%	<u>M</u>	<u>SD</u>	Min	Max
Birth order		2.68	1.96	1	11
Number of children		.82	1.4	0	7
Receiving disability					
Yes	84				
No	10				
Don't know	7				
Number of years receiving disability		4.29	1.09	1	6
Age of first diagnosis		24.51	7.93	5	46
Number of psychiatric hospitalizations					
Never been hospitalized	1				
1 - 2	10				
3 - 5	26				
6 - 10	28				
Over 10	32				
Don't know	3				
Most recent psychiatric hospitalization					
Currently hospitalized	11				
Within the last 6 months	22				
6 - 12 months ago	8				
1 - 2 years ago	11				
3 - 5 years ago	20				
Over 5 years ago	23				
Don't know	4				

Table 6. (continued)

Variable	%	<u>M</u>	<u>SD</u>	Min	Max
Current living situation					
Parents' home	8				
Other family members' home	1				
Own home/apartment	54				
Group home	18				
State hospital	12				
Nursing home	4				
County care facility	1				
Ever been homeless					
Yes	14				
No	84				
Don't know	3				
Distance in miles from study participant		355.81	493.59	1	2000

year for psychiatric problems, 32% in the past six months, and 11% were hospitalized at the time of the interview. Despite the apparent severity of these mentally ill individuals, 54% were currently residing in their own home or apartment.

Correlations

Before analyses were performed to test the study hypotheses, zero-order correlations among the outcome variables were performed. Depression was significantly negatively correlated with self-concept, $r(72) = -.73$, $p < .001$. Depression was also significantly positively correlated with impact on relationships, $r(72) = .24$, $p < .05$. There were no other significant correlations among the outcome variables.

Zero-order correlations were also computed among the predictor variables. These correlations are shown in Table 7. Problem-focused coping was significantly positively correlated with emotion-focused coping, $r(71) = .93$, $p < .001$. Both problem and emotion-focused coping were significantly positively correlated with premorbid interpersonal closeness, $r(71) = .27$, $p < .05$, and $r(71) = .25$, $p < .05$, respectively, and subjective burden, $r(71) = .30$, $p < .05$, and $r(71) = .26$, $p < .05$, respectively. Frequency of contact was significantly positively correlated with premorbid interpersonal closeness, $r(72) = .29$, $p < .05$. Time since the onset of the illness was significantly positively correlated with perceived severity of the illness, $r(72) = .25$, $p < .05$. There were no other significant correlations among the predictor variables.

Demographic variables were also correlated with each outcome variable. Only income was significantly correlated with any outcome variables. Income was significantly negatively correlated with depression, $r(71) = -.28$, $p < .05$, and significantly positively correlated with self-concept, $r(71) = .29$, $p < .05$. Additionally, number of stressful life events was significantly positively correlated with depression, $r(72) = .36$, $p < .01$.

Zero-order correlations between the predictor variables and outcome variables were performed. Partial correlations were also performed controlling for income and stressful life events. These correlations are shown in Table 8. Only significant partial correlations will be discussed here. Use of problem-focused coping and use of emotion-focused coping were

Table 7. Correlations Among the Predictor Variables^a

	Problem- focused coping	Emotion- focused coping	Social support	Closeness	Subjective burden	Time since onset	Frequency of contact	Controll- ability
Emotion-focused coping	.93***							
Social support	.10	.13						
Closeness	.27*	.25*	.03					
Subjective burden	.30*	.26*	.13	-.02				
Time since onset	-.12	-.22	-.14	.00	.01			
Frequency of contact	.14	.13	.04	.29*	.08	.06		
Controllability	-.06	-.07	-.08	.08	-.22	-.04	.01	
Severity	-.05	-.02	-.02	-.06	.02	.25*	-.08	-.16

^a N = 74

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 8. Correlations and Partial Correlations^a Between Predictor and Outcome Variables^b

	Depression		Self-concept		Impact on relationships		Impact on roles	
	r	pr	r	pr	r	pr	r	pr
Problem-focused coping	.02	-.10	.12	.18	-.41***	-.47***	.07	.06
Emotion-focused coping	.03	-.13	.13	.22	-.46***	-.55***	.06	.06
Social support	-.47***	-.50***	.51***	.44***	-.13	-.16	-.07	-.11
Closeness	-.24*	-.20	.16	.15	-.14	-.13	.09	.09
Subjective burden	.15	.06	.02	.02	.19	.17	.25*	.27*
Time since onset	-.01	.11	-.05	-.17	.13	.20	.05	.02
Frequency of contact	-.05	.00	.09	.04	-.13	-.12	.30**	.30*
Controllability	.03	.03	-.06	-.08	.05	.06	.00	-.02
Severity	-.01	-.05	.02	.04	.02	.03	.23*	.23

^a Partial correlations controlling for income and stressful life events

^b N = 74

*p < .05. **p < .01. ***p < .001.

significantly negatively correlated with impact on relationships, $\underline{pr}(67) = -.47$, $\underline{p} < .001$ and $\underline{pr}(67) = -.55$, $\underline{p} < .001$, respectively. Perceived social support was significantly negatively correlated with depression, $\underline{pr}(67) = -.50$, $\underline{p} < .001$, and significantly positively correlated with self-concept, $\underline{pr}(67) = .44$, $\underline{p} < .001$. Frequency of contact with the mentally ill sibling and subjective burden of the illness on the subject were significantly positively correlated with impact on role functioning of the subject, $\underline{pr}(67) = .30$, $\underline{p} < .05$ and $\underline{pr}(67) = .27$, $\underline{p} < .05$, respectively.

Hypothesis Testing

Overview of analyses. For hypotheses 1 through 3, I tested for correlations and partial correlations between the predictor and outcome variables. For hypotheses 4 through 7, I tested for interaction effects using multiple regression analyses. I also performed some additional analyses. In these, I tested for buffering effects that were not formally hypothesized using multiple regression analyses.

Hypothesis 1: It was hypothesized that the more severe the sibling's mental illness, the greater its negative impact would be on the adjustment of well siblings. Specifically, it was hypothesized that high perceived severity of the sibling's mental illness would be associated with high levels of depression, low self-concept, high impact on relationships, and high impact on roles. To test this hypothesis, correlation and partial correlation (controlling for income and stressful life events) analyses were performed for each of the four dependent variables.

As shown in Table 8, perceived severity of the illness was significantly positively correlated with impact on roles when not controlling for income and life events, $\underline{r}(72) = .23$, $\underline{p} < .05$. However, when controlling for income and life events, the relation was no longer significant. Perceived severity was not significantly correlated with depression, self-concept, or impact on relationships.

Hypothesis 2: It was hypothesized that frequency of contact with a mentally ill sibling would have a negative effect on the well sibling's adjustment. Specifically, it was hypothesized that high frequency of contact with the mentally ill sibling would be associated with high levels of depression, low self-concept, high impact on relationships, and high impact

on roles. To test this hypothesis, correlation and partial correlation (controlling for income and stressful life events) analyses were performed for each of the four dependent variables.

As shown in Table 8, frequency of contact with the ill sibling was significantly positively correlated with impact on roles when controlling for income and life events, $r(67) = .30, p < .05$. Frequency of contact was not significantly correlated with depression, self-concept, or impact on relationships.

Hypothesis 3: It was hypothesized that the effects of having a mentally ill sibling would change over time. Specifically, it was hypothesized that less time since the onset of the mental illness would be associated with high levels of depression, low self-concept, high impact on relationships, and high impact on roles. To test this hypothesis, correlation and partial correlation (controlling for income and stressful life events) analyses were performed for each of the four dependent variables.

Time since the onset of the illness was not significantly correlated with depression, self-concept, impact on relationships, or impact on roles.

Hypothesis 4: It was hypothesized that the perception of uncontrollability in situations related to a sibling's mental illness would have a negative impact on adjustment in well siblings. In addition, it was hypothesized that the use of emotion-focused coping behaviors would buffer this effect. Specifically, it was hypothesized that there would be an interaction between the use of emotion-focused coping behaviors and controllability of the consequences of an event related to the mentally ill sibling in the prediction of depression, self-concept, impact on relationships, and impact on roles. It was predicted that the association between uncontrollable events and negative outcomes would be weaker when much emotion-focused coping was used than when little emotion-focused coping was used. To test this hypothesis, a regression analysis was performed for each of the four dependent variables. For each analysis, variables were entered in the following order. First, income and stressful life events were entered to control for their effects. Second, the use of emotion-focused coping behaviors and the controllability of consequences were entered as a block. Third, the use of emotion-focused coping behaviors and controllability were standardized and

multiplied together to form an interaction term. This interaction term was entered after the main effects.

There were no significant interactions between use of emotion-focused coping behaviors and perceived controllability in the prediction of depression, self-concept, impact on relationships, or impact on roles.

Hypothesis 5: It was hypothesized that the use of problem-focused coping would buffer the effects of controllable events related to the sibling's illness on adjustment. Specifically, it was hypothesized that there would be an interaction between the use of problem-focused coping behaviors and controllability of the consequences of an event related to the mentally ill sibling in the prediction of depression, self-concept, impact on relationships, and impact on roles. It was predicted that the association between controllable stressors and negative outcomes would be weaker when problem-focused coping was used often than when it was used infrequently. To test this hypothesis, a regression analysis was performed for each of the four dependent variables. For each analysis, variables were entered in the following order. First, income and stressful life events were entered to control for their effects. Second, the use of problem-focused coping behaviors and the controllability of consequences were entered as a block. Third, the use of problem-focused coping behaviors and controllability were standardized and multiplied together to form an interaction term. This interaction term was entered after the main effects.

There were no significant interactions between use of problem-focused coping behaviors and perceived controllability in the prediction of depression, self-concept, impact on relationships, or impact on roles.

Hypothesis 6: It was hypothesized that premorbid interpersonal closeness with the ill sibling would have a negative effect on the well sibling's adjustment. In addition, it was hypothesized that perceived social support would buffer this impact. Specifically, it was hypothesized that there would be an interaction between interpersonal closeness with the mentally ill sibling prior to the onset of the illness and perceived social support in the prediction of depression, self-concept, impact on relationships, and impact on roles. It was predicted that the positive association between premorbid interpersonal closeness and

depression, impact on relationships, and impact on roles, and the negative association between premorbid interpersonal closeness and self-concept would be stronger when perceived social support was low than when perceived social support was high. To test this hypothesis, a regression analysis was performed for each of the four dependent variables. For each analysis, variables were entered in the following order. First, income and stressful life events were entered to control for their effects. Second, the interpersonal closeness and perceived social support were entered as a block. Third, interpersonal closeness and perceived social support were standardized and multiplied together to form an interaction term. This interaction term was entered after the main effects.

There were no significant interactions between premorbid interpersonal closeness and perceived social support in the prediction of depression, self-concept, impact on relationships, or impact on roles.

Hypothesis 7: It was hypothesized that subjective burden of the mentally ill sibling would have a negative impact on the well sibling's adjustment. In addition, it was hypothesized that the perception of social support would buffer this impact. Specifically, it was hypothesized that there would be an interaction between subjective burden of the mentally ill sibling and perceived social support in the prediction of depression, self-concept, impact on relationships, and impact on roles. It was predicted that the positive association between subjective burden and depression, impact on relationships, and impact on roles, and the negative association between subjective burden and self-concept would be stronger when perceived social support was low than when perceived social support was high. To test this hypothesis, a regression analysis was performed for each of the four dependent variables. For each analysis, variables were entered in the following order. First, income and stressful life events were entered to control for their effects. Second, subjective burden and perceived social support were entered as a block. Third, subjective burden and perceived social support were standardized and multiplied together to form an interaction term. This interaction term was entered after the main effects.

There were no significant interactions between subjective burden and perceived social support in the prediction of depression, self-concept, impact on relationships, or impact on roles.

Exploratory Analyses

The hypotheses for this study were based on the literature on stress, coping, and social support. In addition to the buffering effects tested in the study hypotheses, the literature suggests that coping and social support may have buffering effects for additional constructs assessed in this study. Therefore, several additional interaction analyses were performed to test the buffering effects of coping and social support that were not formally hypothesized. These analyses were performed on an exploratory basis.

As mentioned earlier, problem-focused and emotion-focused coping were highly correlated, $r(71) = .93$, $p < .001$. Because the hypotheses regarding the use of coping behaviors predicted differential effects for problem-focused and emotion-focused coping, they were left as separate constructs for hypothesis testing. However, for the following exploratory analyses, problem-focused and emotion-focused coping were combined to form an overall measure of coping. These eight items had a Cronbach's alpha of .62.

Analysis 1: A regression analysis was performed to test the interaction between the use of coping behaviors and the frequency of contact with the mentally ill sibling in the prediction of the dependent variables (depression, self-concept, impact on relationships, and impact on roles). For each analysis, variables were entered in the following order. First, income and stressful life events were entered to control for their effects. Second, the use of coping behaviors and the frequency of contact were entered as a block. Third, the use of coping behaviors and the frequency of contact were standardized and multiplied together to form an interaction term. This interaction term was entered after the main effects.

Very similar significant interactions were found when predicting both depression and self-concept. Since depression and self-concept are so highly negatively correlated, $r(72) = -.73$, $p < .001$, the 19 items measuring self-concept were reversed and summed with the 20 depression items to form an overall measure of psychological distress. These 39 items had a

Cronbach's alpha of .95. The analysis was performed again using the psychological distress measure.

Two significant interactions were found. First, there was a significant interaction between the use of coping behaviors and frequency of contact in the prediction of psychological distress, change in $R^2 = .05$, $F(5,66) = 4.21$, $p < .05$. The results of this regression analysis are shown in Table 9. Shown in Figure 1 are the means, 25th percentiles, and 75th percentiles of frequency of contact and psychological distress for low and high users of coping. The mean frequency of contact score for the low coping group was 8 (25th percentile = 5, 75th percentile = 10); for the high coping group the mean frequency of contact score was 9 (25th percentile = 6, 75th percentile = 10.25). The mean psychological distress score for the low coping group was 65.23 (25th percentile = 61.96, 75th percentile = 67.41); however, for the high coping group the mean psychological distress score was 62.08 (25th percentile = 65.98, 75th percentile = 60.46). Thus, when use of coping was low, frequency of contact with the mentally ill sibling was significantly positively correlated with psychological distress; when use of coping was high, frequency of contact with the mentally ill sibling was significantly negatively correlated with psychological distress. Despite lack of significant differences between the means of the two groups on psychological distress, the effective use of coping behaviors does buffer the effects of frequency of contact on psychological distress.

Second, there was a significant interaction between the use of coping behaviors and frequency of contact in the prediction of impact on relationships, change in $R^2 = .06$, $F(5,66) = 5.72$, $p < .05$. See Table 10 for the results of this regression analysis. Figure 2 shows the means, 25th percentiles, and 75th percentiles of frequency of contact and impact on relationships for low and high coping groups. The mean, 25th, and 75th percentile frequency of contact scores for the low and high coping groups are the same as above. The mean impact on relationships score for the low coping group was 19.82 (25th percentile = 19.61, 75th percentile = 19.96); however, for the high coping group the mean impact on

Table 9. Summary of Hierarchical Regression Analysis for the Interaction Between Frequency of Contact and Coping in Predicting Psychological Distress (N = 74)

Variable	<u>B</u>	<u>SE B</u>	Beta
Step 1			
Income	-2.67	1.27	-0.24*
Life events	1.71	0.70	0.28*
Step 2			
Income	-2.60	1.28	-0.23*
Life events	1.97	0.74	0.32**
Frequency of contact	0.11	0.65	0.02
Coping	-0.15	0.12	-0.14
Step 3			
Income	-2.10	1.27	-0.19
Life events	1.81	0.72	0.29*
Frequency of contact	0.23	0.64	0.04
Coping	-0.14	0.12	-0.14
Frequency of contact X Coping	-3.04	1.48	-0.23*

Note. $R^2 = .17^{**}$ for Step 1; $\Delta R^2 = .02$ for Step 2; $\Delta R^2 = .05^*$ for Step 3. The y-intercept for the final regression equation equals 73.31.

* $p < .05$. ** $p < .01$. *** $p < .001$.

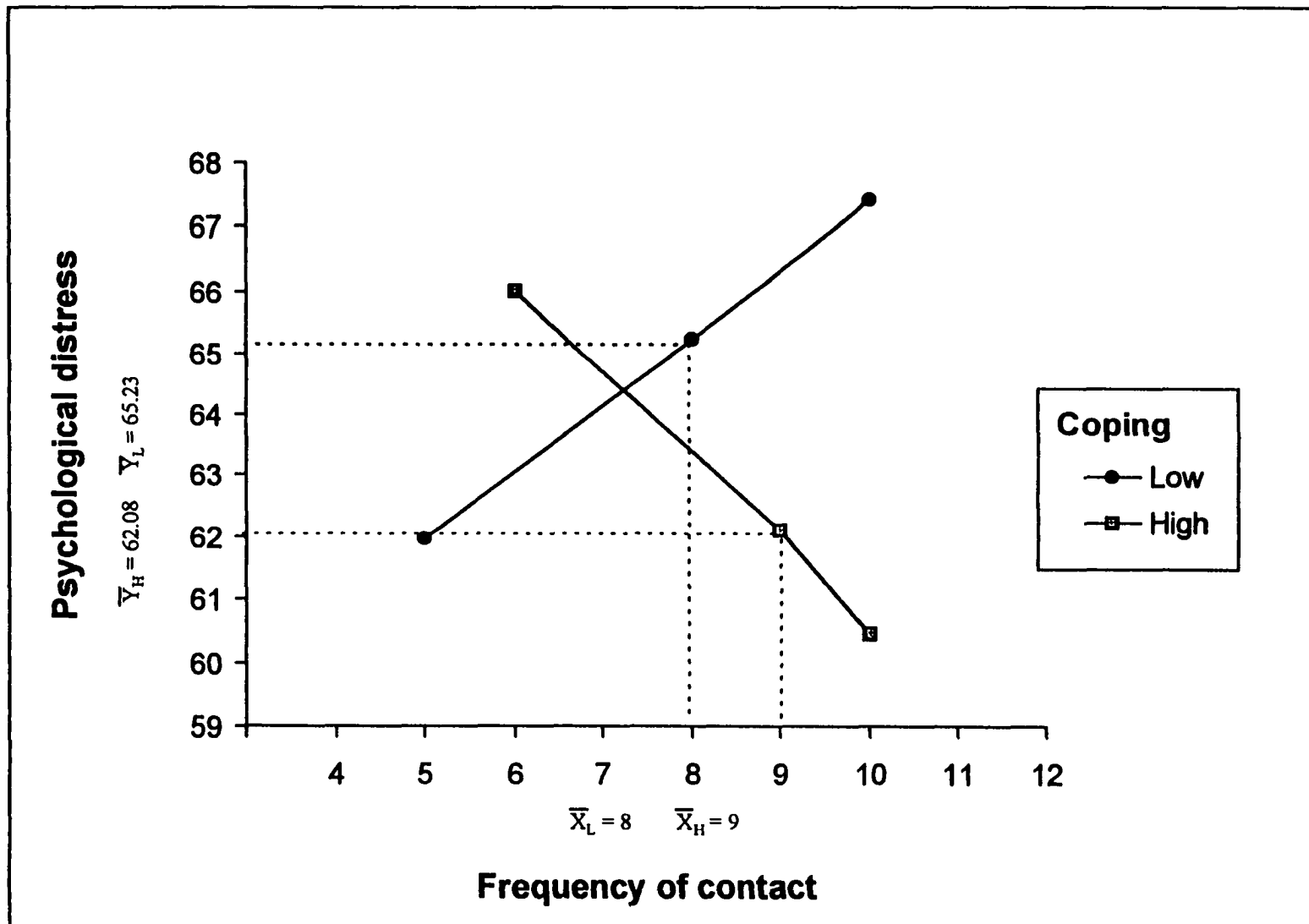


Figure 1. The Interaction Between Frequency of Contact and Coping in Predicting Psychological Distress.

Table 10. Summary of Hierarchical Regression Analysis for the Interaction Between Frequency of Contact and Coping in Predicting Impact on Relationships (N = 74)

Variable	<u>B</u>	<u>SE B</u>	Beta
Step 1			
Income	-0.35	0.29	-0.15
Life events	0.14	0.16	0.11
Step 2			
Income	-0.27	0.25	-0.11
Life events	0.34	0.15	0.26*
Frequency of contact	-0.04	0.13	-0.04
Coping	-0.11	0.02	-0.51***
Step 3			
Income	-0.15	0.25	-0.07
Life events	0.31	0.14	0.23*
Frequency of contact	-0.02	0.13	-0.01
Coping	-0.11	0.02	-0.50***
Frequency of contact X Coping	-0.70	0.29	-0.25*

Note. $R^2 = .04$ for Step 1; $\Delta R^2 = .24^{***}$ for Step 2; $\Delta R^2 = .06^*$ for Step 3. The y-intercept for the final regression equation equals 26.33.

* $p < .05$. ** $p < .01$. *** $p < .001$.

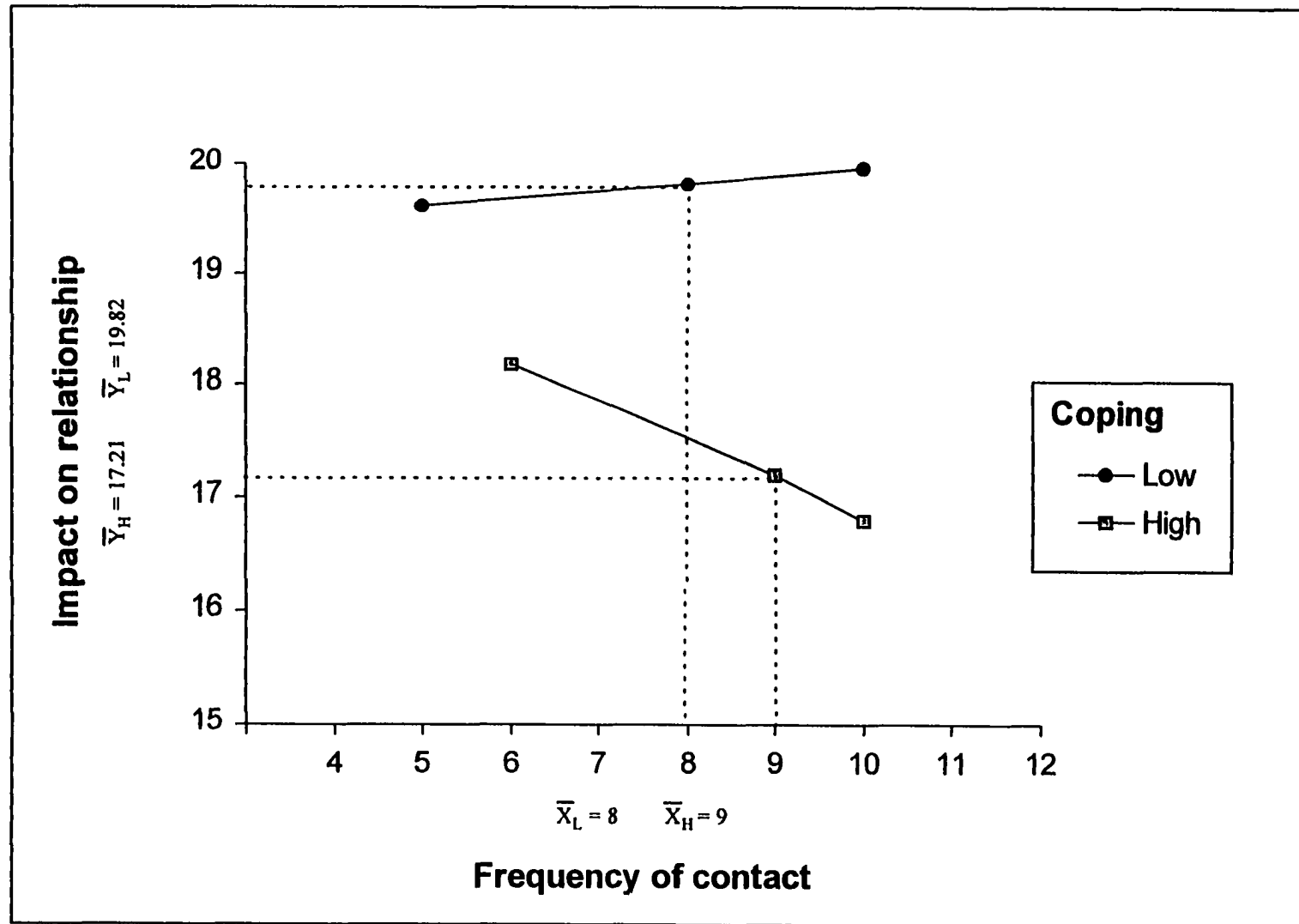


Figure 2. The Interaction Between Frequency of Contact and Coping in Predicting Impact on Relationships.

relationships score was 17.21 (25th percentile = 18.17, 75th percentile = 16.81). Thus, when use of coping was low, frequency of contact with the mentally ill sibling was significantly positively correlated with impact on relationships; when use of coping was high, frequency of contact with the mentally ill sibling was significantly negatively correlated with impact on relationships. Again, despite lack of significant differences between the means of the two groups on impact on relationships, the effective use of coping behaviors does buffer the effects of frequency of contact on impact on relationships.

There was not a significant interaction between use of coping behaviors and frequency of contact in the prediction of impact on roles.

Analysis 2: A regression analysis was performed to test the interaction between the use of coping behaviors and the perceived severity of the mental illness in the prediction of the dependent variables (depression, self-concept, impact on relationships, and impact on roles). For each analysis, variables were entered in the following order. First, income and stressful life events were entered to control for their effects. Second, the use of coping behaviors and the frequency of contact were entered as a block. Third, the use of coping behaviors and the frequency of contact were standardized and multiplied together to form an interaction term. This interaction term was entered after the main effects.

There was a significant interaction between the use of coping behaviors and perceived severity of the illness in the prediction of depression, change in $R^2 = .08$, $F(5,66) = 7.79$, $p < .01$. The results of this regression analysis are shown in Table 11. Shown in Figure 3, are the means, 25th percentiles, and 75th percentiles of perceived severity and depression for low and high users of coping. The mean perceived severity score for the low coping group was 15 (25th percentile = 13, 75th percentile = 17); for the high coping group the mean perceived severity score was 14 (25th percentile = 13, 75th percentile = 16.25). The mean depression score for the low coping group was 30.69 (25th percentile = 30.09, 75th percentile = 31.29); for the high coping group the mean depression score was 30.59 (25th percentile = 31.35, 75th percentile = 28.88). Thus, when use of coping was low, perceived severity was significantly positively correlated with depression; when use of

Table 11. Summary of Hierarchical Regression Analysis for the Interaction Between Severity and Coping in Predicting Depression (N = 74)

Variable	<u>B</u>	<u>SE B</u>	Beta
Step 1			
Income	-1.25	0.75	-0.19
Life events	1.40	0.41	0.37**
Step 2			
Income	-1.17	0.76	-0.17
Life events	1.52	0.44	0.41***
Severity	-0.20	0.47	-0.05
Coping	-0.06	0.07	-0.10
Step 3			
Income	-1.36	0.73	-0.20
Life events	1.77	0.43	0.47***
Severity	-0.22	0.45	-0.05
Coping	-0.08	0.07	-0.12
Severity X Coping	-2.82	1.01	-0.30**

Note. $R^2 = .21^{***}$ for Step 1; $\Delta R^2 = .01$ for Step 2; $\Delta R^2 = .08^{**}$ for Step 3. The y-intercept for the final regression equation equals 37.00.

* $p < .05$. ** $p < .01$. *** $p < .001$.

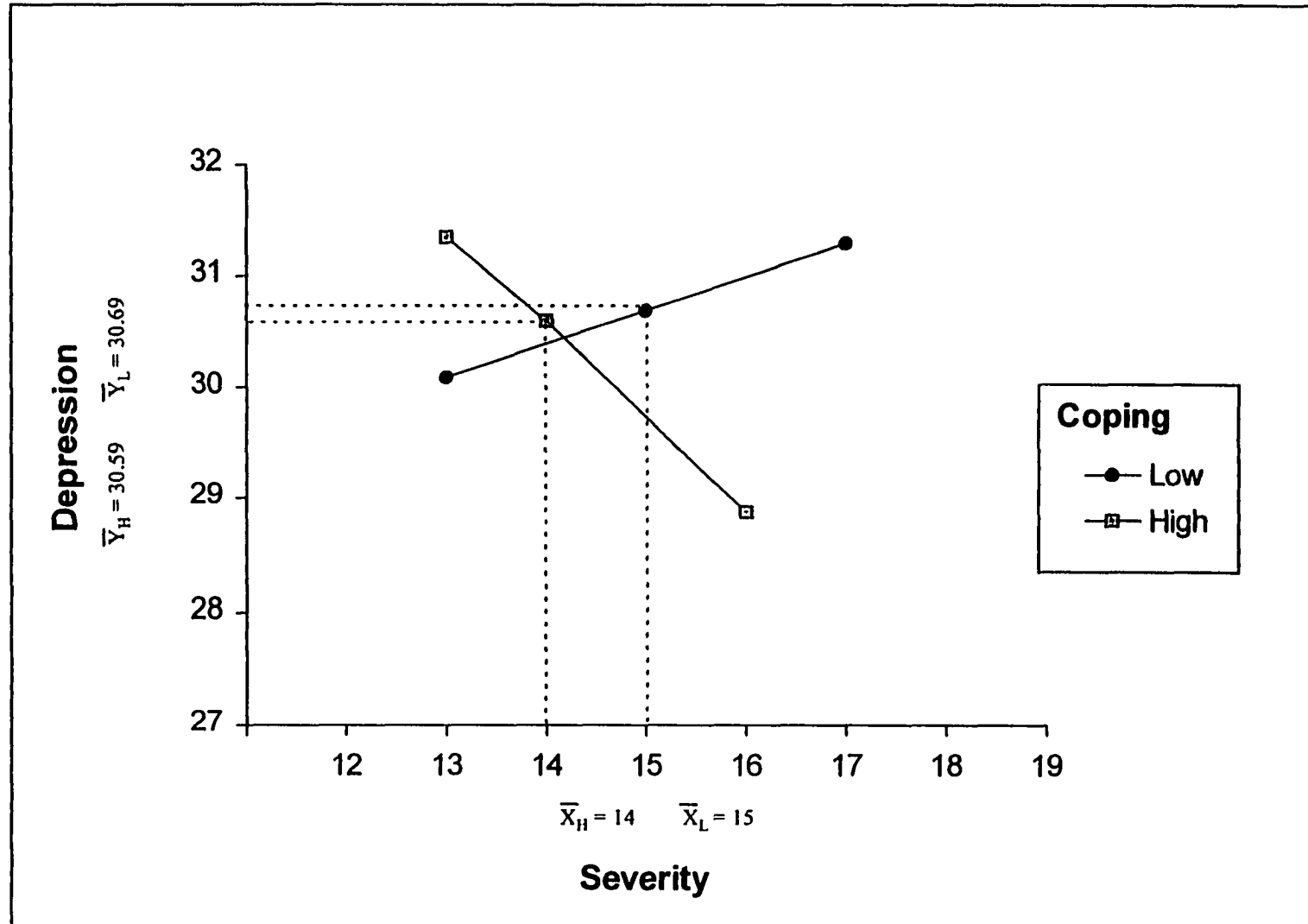


Figure 3. The Interaction Between Severity and Coping in Predicting Depression.

coping was high, perceived severity was significantly negatively correlated with depression. Despite lack of significant differences between the means of the two groups on depression, the effective use of coping behaviors does buffer the effects of perceived severity on depression.

There were no significant interactions between use of coping behaviors and perceived severity in the prediction of self-concept, impact on relationships, or impact on roles.

DISCUSSION

This study was designed to assess the effects of having a sibling with schizophrenia or a related disorder on depression, self-concept, relationships, and daily role functioning. The study addressed several of the methodological flaws that existed in previous research on siblings of individuals with schizophrenia or a related disorder. Specifically, study participants were recruited from a variety of recruitment sources (e.g., hospitals, support groups, community programs). In addition, only one person per family was interviewed in this study. Finally, this study had a relatively large sample size for this type of research.

There were seven study hypotheses and each hypothesis included four predictions (one for each of four dependent variables). Out of those 28 predictions, two were supported. However, exploratory analyses based on the literature produced a number of interesting findings that were not predicted.

Adverse Effects of Mental Illness on Well Siblings

The first set of questions that was posed in this study concerned the adverse effects of having a sibling with a chronic mental illness on adjustment in well siblings. The first question posed was, "Does the perceived severity of the mental illness affect how well siblings adjust to a mental illness in a brother or sister?" It was predicted that high perceived severity of the sibling's mental illness would be associated with high levels of depression, low self-concept, high impact on relationships, and high impact on roles. Perceived severity was indeed associated with functioning in daily roles of well siblings. Perceived severity was not associated with depression, self-concept, or impact on relationships. This would suggest that perceived severity of a sibling's mental illness only disrupts functioning in daily roles and does not affect other aspects of adjustment in well siblings. However, a possible explanation for the paucity of significant correlations is low variance in the perceived severity measure. The mean perceived severity of their sibling's illness as rated by the participants was very high. Possible perceived severity scores ranged from 4 to 18. For this sample, the mean perceived severity score was 14.61 with a standard deviation of 2.35 (see Table 3). Restriction of range may have prevented significant correlations with three of the four outcome measures.

The second question asked was "Do people who have more contact with their mentally ill sibling differ in their adjustment to the illness from those who have less frequent contact?" It was predicted that high frequency of contact with the mentally ill sibling would be associated with high levels of depression, low self-concept, high impact on relationships, and high impact on roles. Frequency of contact was indeed associated with functioning in daily roles of well siblings. Frequency of contact was not, however, related to depression, self-concept, or impact on relationships. This would suggest that, like perceived severity of the illness, frequent contact with a mentally ill sibling only disrupts functioning in daily roles and does not affect other aspects of adjustment in well siblings.

The third question was "Do the effects of a sibling's mental illness change over time?" It was predicted that less time since the onset of the mental illness would be associated with high levels of depression, low self-concept, high impact on relationships, and high impact on roles. Time since the onset of the illness was not related to depression, self-concept, impact on relationships, or impact on functioning in daily roles. This suggests that length of time since the onset of the illness does not have any effects on well sibling's adjustment. However, only one participant in this study reported the time since the onset of the illness to be less than 3 years. The mean number of years since the onset of the illness was 18.86 with a standard deviation of 10.99 (see Table 3). It may be that there would have been more significant findings had there been a more diverse sample with regards to time since the onset of the illness.

In addition to those predicted, exploratory analyses produced three additional trends. First, both problem-focused and emotion-focused coping were related to impact of the sibling's illness on other relationships. This association remained significant when controlling for income and stressful life events. How one copes with having a sibling with a mental illness is related to the impact of the sibling's illness on one's relationships with others. Thus, it appears that the use of coping strategies is related to interpersonal functioning, or how one functions with others.

Second, perceived social support was related to depression and self-concept. These relations held when controlling for income and stressful life events. These associations are

consistent with the literature on social support (Brown & Harris, 1978; Cohen & Wills, 1985; Gore, 1978). It appears that perceived social support is related to intrapersonal functioning, or how one functions within him or herself.

Third, subjective burden was related to impact on functioning in daily roles. Lively, et al. (1995) found that having a sibling with a mental illness affected functioning in daily roles. They did not, however, examine what specific aspects of sibling mental illness affected this functioning. This finding identifies what aspects of having a sibling with a chronic mental illness affects functioning in daily roles. Thus, it appears that subjective burden, frequency of contact, and perceived severity all tend to be related to the disruption of functioning in daily tasks.

In summary, it appears that the extent to which having a mentally ill sibling affects how one functions in interpersonal relationships is more closely related to how one copes with that stress than any of the other factors examined. Intrapersonal issues, or how one functions within oneself (e.g., depression, self-concept), are more closely related to issues of how available one perceives support to be than other factors examined. And, the extent to which having a sibling with a mental illness disrupts functioning in daily roles is more closely related to issues that directly involve the ill sibling (e.g., subjective burden of the illness, frequency of contact with the ill sibling, and perceived severity of the illness) than other factors examined.

Protection Against Adverse Effects

Having a sibling with a chronic mental illness like schizophrenia does have adverse effects on adjustment in well siblings. What then protects individuals against the negative effects of having a sibling with a chronic mental illness? The first question examining these buffering effects asked, "To what extent does using emotion-focused coping protect one against the adverse effects of feeling no control over the mental illness on well sibling adjustment?" Based on Folkman and Lazarus (1980), it was predicted that using emotion-focused coping would protect one against the adverse effects of feeling no control. However, feeling a lack of control over the sibling's mental illness was not related to depression, self-concept, impact on relationships, or impact on daily roles. It may be that controllability does

not affect the impact that having a sibling with a mental illness has on adjustment. Alternatively, this particular measure of controllability may not be a valid measure. Using emotion-focused coping behaviors did not seem to make a difference on the effects of uncontrollability. However, the reliability of the emotion-focused coping measure was low. Thus, it may be that the lack of significant findings for this hypothesis can be accounted for by low reliability of the coping measure and a lack of relationship between controllability and the outcome variables.

The second question was very similar to the first and asked, "To what extent does using problem-focused coping protect one against the adverse effects of feeling no control over the mental illness on well sibling adjustment?" Based on Folkman and Lazarus (1980), it was predicted that problem-focused coping would be most beneficial for those who perceived high control over events related to a sibling's mental illness. As mentioned above, controllability was not related to adjustment. Likewise, using problem-focused coping did not seem to influence the effects of controllability. Problem-focused coping also had low reliability. Therefore, the same methodological arguments made above hold for this hypothesis.

The third question asked, "To what extent does having people to turn to for help protect one against the adverse effects of feeling close to one's mentally ill sibling before they became ill in the adjustment of well siblings?" Those who were especially close to their sibling before the onset of his or her illness were expected to suffer a greater sense of loss than those who were not ever very close to their ill sibling. It was predicted that this sense of loss would be lessened by perceived social support from those in the individual's current social network. However, the extent that an individual felt close to their ill sibling before they became ill was not found to be related to depression, self-concept, impact on relationships, or impact on daily roles. Social support did not alter the effects of relationship closeness with the ill sibling.

The final question was, "To what extent does having people to turn to for help protect one against the adverse effects of feeling that a mentally sibling is a burden?" It was predicted that for people who felt they had more social support, there would be less of an adverse effect on adjustment from feeling that their mentally ill sibling was a burden, compared

to those who felt they had less social support. That is, having someone to turn to would protect one against the adverse effects of feeling burdened by the mentally ill sibling. These predicted buffering effects were not found.

Exploratory analyses produced interesting buffering effects were found that were not formally hypothesized. It was found that for people who used much coping, more frequent contact with the mentally ill sibling was related to less psychological distress and less impact on relationships. However, for people who used little coping, more frequency of contact with the mentally ill sibling was related to more psychological distress and more impact on relationships. That is, using coping protected individuals from the adverse effects of having frequent contact with their mentally ill sibling.

Similarly, it was found that for people who used much coping, perceptions of greater severity of their sibling's mental illness were related to lower depression. However, for people who used little coping, perceptions of greater severity of their sibling's mental illness were related to higher depression. That is, using coping protected individuals from the adverse effects of perceiving the illness to be severe.

It appears that the use of effective coping strategies does have a buffering effect on adjustment in well siblings. In particular, use of coping appears to protect individuals from the adverse effects of having contact with their mentally ill siblings on psychological distress and impact on other relationships. In addition, use of coping appears to protect individuals from the adverse effects of severe sibling illness on depression. These findings are post hoc and therefore must be replicated. However, these findings do have important implications for the use of coping interventions with siblings of the chronically mentally ill.

Clinical Implications

Based on the findings from this study, three aspects of sibling mental illness were found to have direct adverse effects on daily role functioning. The amount of burden one perceives the mentally ill sibling to be, how often the well sibling has contact with the mentally ill sibling, and how severe the illness is perceived to be were all directly related to the impact the illness had on functioning in daily roles such as performance at work and in school. This finding has direct clinical implications for working with siblings of the mentally ill. Therefore,

educational approaches and therapeutic interventions that focus on alleviating burden, decreasing frequency of contact, and reframing the severity of the illness would be beneficial.

Another direct adverse effect of sibling mental illness that has important clinical implications emerged from this study. As has been found in numerous previous research studies with various samples, perceived social support was directly related to depression and self-concept. This finding suggests that it is important to train individuals who have siblings with a chronic mental illness to increase their supportive resources. Such social support interventions may be helpful in alleviating the adverse effects of sibling mental illness on depression and self-concept.

What protects individuals from suffering associated with having a mentally ill sibling? One consistent theme emerged from this study. The use of coping behaviors protect individuals across several domains. Use of coping appears to protect individuals from the adverse effects of having contact with their mentally ill siblings. In addition, use of coping appears to protect individuals from the adverse effects of the severity of the mental illness. In addition, a direct relation was found between the use of these coping strategies and an impact on other relationships. These findings strongly suggest that psychoeducational training of siblings of the mentally ill in the use of problem-focused and emotion-focused coping strategies would be beneficial to adjustment to having a sibling with schizophrenia or a related illness.

In summary, there are several clinical implications derived from the findings of this study. First, educational approaches and therapeutic interventions that focus on alleviating burden, decreasing frequency of contact, and reframing the severity of the illness may be beneficial in decreasing the adverse effects on functioning in daily roles associated with having a sibling with a chronic mental illness. Second, social support interventions may be helpful in alleviating the adverse effects of sibling mental illness on depression and self-concept. And third, psychoeducational interventions that focus on the use of effective coping strategies may buffer the effects of sibling mental illness on depression, self-concept, and relationships with others.

Limitations of the Study

Several limitations to this study should be noted. First, a sample size of 74 may not be large enough to detect significant relationships. For each regression analysis that was performed there were two control variables (which accounted for up to 21% of the variance), two predictor variables, and an interaction term. A power analysis (Cohen, 1977) was conducted and indicated that 90 participants would be needed to detect a moderate effect size. Due to difficulty in recruiting additional subjects and financial constraints, only 74 participants were interviewed in this study. In addition, the reliability of several of the measures was low. Because of the relatively small sample size, the number of variables for each analysis, and the low reliability on several of the measures, there may not have been enough power to detect significant effects.

Second, due to the social stigma associated with mental illness and the nature of the information gathered, two forms of sample bias may have occurred in this study. First, contact sources (e.g., AMI group members, patients, residential facility workers) may have been biased in whether or not they felt the potential participant would be interested in participating in this study. They may have been more likely to refer or contact potential participants who had stronger relationships with their mentally ill siblings than those who did not. For example, in several cases the referral source informed me that they chose which potential participants to approach. Therefore, the individuals who were chosen to participate may have been biased to respond to the questionnaire in a certain manner due to the nature of their relationship with their mentally ill sibling. Second, it was difficult to find participants. Despite using care to obtain participants from a variety of recruitment sources, it is likely that there are sources of participants that were never tapped. For example, it would be difficult to obtain the names of potential participants who have not had contact with their mentally ill sibling for a long time. Likewise, mentally ill individuals who were homeless would not likely be included as a recruitment source. Therefore, the mentally ill individuals who have become detached from their families may not have been included. It is difficult to determine the extent to which this study sample is biased from either of these sources, but it is likely that a bias does exist.

Another limitation of this study relates to the diagnosis of the mentally ill sibling. Complete accuracy in diagnosis of the ill sibling was impossible. Although every care was taken to ensure that all participants met the criteria (e.g., having a sibling with schizophrenia or a related illness), several of the participants reported diagnoses that were not appropriate (e.g., bipolar affective disorder) or did not know what the diagnosis was. These participants were included in the study because accurate diagnosis was verified by another source (e.g., medical records or recruitment source). However, having access to the ill sibling's medical records would have been helpful.

The use of a control group would have strengthened the study. It would have been beneficial to compare siblings of those with a chronic mental illness with siblings of those with a chronic physical illness (e.g., Insulin Dependent Diabetes Mellitus). Comparison to a group of siblings of those with neither a chronic mental or physical illness would have been desirable as well. It is difficult to know if this sample is different from a normative sample or a sample of siblings of individuals with a chronic physical illness.

Despite wide variability in the time since the onset of the mental illness (range from 2 years to 50 years), only one participant's mentally ill sibling had been diagnosed with a mental illness less than three years earlier. It is likely that participants with recently diagnosed siblings (0-3 years) may respond differently to the study questions than those whose siblings' time since onset is longer. It may be that the amount of time since the onset of the mental illness does have an effect, but this sample was not diverse enough to detect it.

The perceived severity of the mental illness was predicted to affect the well sibling's adjustment. However, there was little variance in the ratings of perceived severity in this sample. The majority of the participants reported the sibling's mental illness to be very severe. The relation between perceived severity and adjustment may not have been detected because of restriction of range.

It can be argued that the responses to the questions in this study may have been biased due to the varied roles of the primary investigator. The primary investigator reviewed the literature, developed the hypotheses, developed the questionnaire, and conducted all of the interviews. Therefore, the interviewer may have unknowingly biased the responses of

the participants to fit the study hypotheses. However, the interview was highly structured in every attempt to avoid such a bias. In addition, this argument would be more likely had the study hypotheses been supported.

Directions for Future Research

Even though it makes intuitive sense that coping would buffer the effects of certain aspects of sibling's mental illness on well sibling's adjustment, possible alternative interpretations may exist. One way to test whether or not this interpretation is accurate would be to conduct an intervention study. This study would be a pre- and post-test design which would involve having a group of siblings of people with mental illness like schizophrenia and teaching them effective coping strategies. If the teaching of these coping strategies were effective (e.g., the siblings were able to learn and implement effective coping strategies), then this hypothesis would be supported. If the siblings were unable to learn the use of effective coping strategies, alternative interpretations would have to be explored.

Another implication for future research involves the construct of perceived severity. In this study, the participants described the illness to be very severe. Although the measure of perceived severity of the mental illness had a relatively large range of possible responses, it had very low variance. This low variance could have diminished any significant effects of severity on the well sibling's adjustment. Using a measure that is more sensitive to differences in severity among highly severe populations may generate more significant findings. It is recommended that additional studies of siblings of the mentally ill use such a measure to determine the effects of severity of the mental illness on well sibling adjustment.

Time since the onset of the mental illness was not found to have a significant effect on adjustment in well siblings. For all but one participant, onset of the mental illness was at least two years ago. A sample with a larger number of participants whose siblings had become mentally ill within the last 0-3 years may yield different results. The qualitative study by Carlisle (1984) suggests that reactions to mental illness vary greatly as a function of time since the onset.

General Summary

Having a sibling with a chronic mental illness like schizophrenia can be extremely difficult to adjust to. Based on this study, it appears as though difficulty in adjustment takes several forms. Sibling mental illness can have an impact on how one functions in interpersonal relationships with other people, on how one functions in their daily roles, and on how one functions within themselves (e.g., their mood and how they view themselves). Siblings of individuals with mental illness often view the illness as burdensome. Those who feel the illness is a burden to them, tend to do worse in terms of adjustment. However, having people to turn to for support and advice seems to benefit siblings of the mentally ill.

Interestingly, those siblings who are more involved or have more frequent contact with the ill sibling tend to do worse than those who have less frequent contact with the ill sibling. Fortunately, being able to cope effectively with the stress of having a sibling with a chronic mental illness protects individuals from these negative effects. Siblings of the mentally ill also view the illness as extremely severe, often having little or no hope for improvement or cure. This perception of extreme severity also appears to have an impact on adjustment. However, being able to cope effectively with sibling mental illness also protects individuals from these negative effects.

Having a sibling with a chronic mental illness like schizophrenia does take its toll on how well siblings adjust to the illness. However, having people to provide support during difficult times and learning how to deal effectively with difficult situations can make the adjustment much easier and more positive.

APPENDIX A
LETTERS TO PARTICIPANTS

PATIENT LETTER

Greetings!

I am a graduate student in Psychology at Iowa State University. I am doing a research study of families of people coping with mental illness. I would like to contact brothers or sisters of people coping with mental illness to ask them some questions about mental illness.

You are invited to participate in this study. If you decide to participate, you will be asked to give me your age, and the names, addresses, phone numbers, and ages of your brothers and sisters. That is all you will be asked to do. I will then contact one of them and ask him or her some questions about mental illness. If you do not have the addresses and phone numbers of your brothers and sisters available right now, I would like to contact your parents or legal guardian to get that information.

Your participation in this study is completely voluntary. If you decide not to participate, it will not affect the services you receive at _____. All information is kept confidential. Your name will not be connected with your brother's or sister's information. You should experience no discomfort from participating in this study.

Thank you for thinking about participating in my study. Your participation will help provide important information to mental health professionals who care for families like yours.

If you have any questions about this study, please feel free to contact me, Marcy Halvorson, at (515)279-4584. You may also call the faculty advisor for this study, Dr. Carolyn Cutrona, at (515)294-6784 or (515)294-9400.

Sincerely,

Marcy B. Halvorson, M.S.

Subject Statement

I have been told about this study of families of people coping with mental illness being conducted by Marcy Halvorson from Iowa State University. I voluntarily agree to participate in the study.

Signature of Participant

Date

PATIENT SIBLING LETTER

Greetings!

I am writing regarding a study I am conducting. I am a graduate student in Psychology at Iowa State University. I am doing a research study of families of people coping with mental illness. In particular, I am interested in how brothers and sisters cope with having a sibling with schizophrenia or a related disorder. It is with this regard that I am writing you this letter.

I received your name, address, and phone number from your brother or sister who is coping with mental illness. He or she granted me permission to contact you regarding participation in this study. I will be contacting you by telephone within the next week to ask if you would be willing to set up a telephone interview regarding your experiences of having a brother or sister with a mental illness.

The telephone interview is strictly voluntary and will last approximately 45 minutes. If you are under the age of 18, a parent's permission is required. I will be asking you questions like, "What is the most difficult aspect of having a brother or sister with a mental illness?" and "How has your relationship with your brother or sister changed since the onset of the illness?" The only risk you may face by participating in this study is sadness or anxiety over discussing your brother's or sister's illness. Your participation in this study will in no way affect the treatment or care of your brother or sister.

All information obtained in the interview will be strictly confidential. Your name will not be connected with your information. Instead, a random number will be assigned to your information. In any write ups of results only group information will be reported, that is no individual information.

I greatly appreciate you considering participating in my study. Mental illness not only affects the one who is diagnosed with it, but the family members as well. Your participation in this research study will help provide valuable information to mental health professionals who care for families like yours.

If you have any questions concerning this study, please feel free to call me at (515)279-4584. You may also call the faculty advisor for this project, Dr. Carolyn Cutrona, at (515)294-6784 or (515)294-9400. I am looking forward to talking with you soon.

Sincerely,

Marcy B. Halvorson, M.S.

SUPPORT GROUP LETTER

Greetings!

I am writing regarding a study I am conducting. I am a graduate student in Psychology at Iowa State University. Perhaps you saw my article in the newsletter in April. I am doing a research study of families of people coping with mental illness. In particular, I am interested in how brothers and sisters cope with having a sibling with schizophrenia or a related disorder. It is with this regard that I am writing you this letter.

I received your name, address, and telephone number from _____. I will be contacting you by telephone within the next week to ask if you have, or if you know of someone who has a brother or sister with schizophrenia or a related disorder. If you have a brother or sister with schizophrenia or a related disorder, I will ask if you would be willing to set up a telephone interview regarding your experiences of having a brother or sister with a mental illness. If you know someone who would be appropriate for this study, I will ask you for their name, address, and phone number so that I may contact them.

The telephone interview is strictly voluntary and will last approximately 45 minutes. If you are under the age of 18, a parent's permission is required. I will be asking you questions like, "What is the most difficult aspect of having a brother or sister with a mental illness?" and "How has your relationship with your brother or sister changed since the onset of the illness?" The only risk you may face by participating in this study is sadness or anxiety over discussing your brother's or sister's illness. Your participation in this study will in no way affect your status with _____.

All information obtained in the interview will be strictly confidential. Your name will not be connected with your information. Instead, a random number will be assigned to your information. In any write ups of results only group information will be reported, that is no individual information.

I greatly appreciate you considering participating in my study. Mental illness not only affects the one who is diagnosed with it, but the family members as well. Your participation in this research study will help provide valuable information to mental health professionals who care for families like yours.

If you have any questions concerning this study, please feel free to call me at (515)279-4584. You may also call the faculty advisor for this project, Dr. Carolyn Cutrona, at (515)294-6784 or (515)294-9400. I am looking forward to talking with you soon.

Sincerely,

Marcy B. Halvorson, M.S.

APPENDIX B
INFORMED CONSENT

I am conducting telephone interviews regarding people's experiences with having a brother or sister with a schizophrenia related illness.

The interview will last from 30-45 minutes

The only risk you may face by participating in this study is sadness or anxiety over discussing your brother's or sister's illness

Your participation in this study is voluntary and will in no way affect the treatment or care of your brother or sister

All information obtained in the interview is strictly confidential

Your name or your sibling's name will not be connected with your information

Instead, a random number will be assigned to your information

In any write ups of results only group information will be reported, that is no individual information.

Do you have any questions about what I've talked about so far?

Would you be willing to be interviewed regarding your experiences of having a brother or sister with a mental illness?

(If yes)

Great, is now a convenient time for the interview?

Can we set up a time that is more convenient for you?

(If no)

Can I ask you what is preventing you from participating in this study?

Thank you for your time.

APPENDIX C
SIBLING QUESTIONNAIRE

SIBLING QUESTIONNAIRE

ID: _____

[1] Source:

- 01 Alliance for the Mentally Ill
- 02 Community Access Program
- 03 Broadlawns Inpatient
- 04 Lutheran Inpatient
- 05 Eyerly Ball MHC
- 06 Westminster House
- 07 Department of Human Services
- 08 Rainbow Center
- 09 Veteran's Affairs Medical Center
- 10 South Central Mental Health Center
- 11 River Valley Residential Center
- 99 Other

BACKGROUND INFORMATION

I am going begin by asking you some brief questions about your background.

[2] What is your current marital status?

- 1 Never been married
- 2 Engaged
- 3 Married
- 4 Separated
- 5 Divorced
- 6 Widowed

[3] What is your age?

[4] Gender?

- 1 Male
- 2 Female

[5] What is the highest grade level you have finished?

- 1 Never attended school
- 2 Eighth grade or less
- 3 Some high school
- 4 High school graduate
- 5 Some college, junior college, or trade school
- 6 College graduate
- 7 Beyond college graduate

[6] What is your current employment status?

- 1 Employed, full-time
- 2 Employed, part-time
- 3 Not employed

[7] What is your annual household income?

- 1 \$0 - \$15,000
- 2 \$15,001 - \$30,000
- 3 \$30,001 - \$45,000
- 4 \$45,001 - \$60,000
- 5 \$60,001 - \$75,000
- 6 Over \$75,000

During the rest of this interview, I will be asking you some questions regarding your brother or sister who has been identified in this study.

Would you tell me his/her first name?

[name] _____

[8] Gender?

- 1 Male
- 2 Female

[9] What is his/her age?

[10] What is your blood relation to [name]?

- 1 Biological sibling
- 2 Identical twin
- 3 Fraternal twin
- 4 Step-sibling
- 5 Half-sibling
- 6 Adopted sibling

[11] How many brothers and sisters do you have?

[12] Where do you fall in the birth order?

[13] Where does [name] fall in the birth order?

[14] What is [name's] marital status:

- 1 Never been married
- 2 Engaged
- 3 Married
- 4 Separated
- 5 Divorced
- 6 Widowed

[15] How many children does [name] have?

[16] What is the highest grade level [name] has finished?

- 1 Never attended school
- 2 Eighth grade or less
- 3 Some high school
- 4 High school graduate
- 5 Some college, junior college, or trade school
- 6 College graduate
- 7 Beyond college graduate

[17] What is [name's] current employment status?

- 1 Employed, full-time
- 2 Employed, part-time
- 3 Not employed

[18] Is [name] currently receiving disability for his/her mental illness?

- 1 Yes
- 2 No
- 3 Don't know

[19] If yes, for how many years has [name] received disability?

- 1 0 - 1 years
- 2 1 - 2 years
- 3 3 - 4 years
- 4 5 - 10 years
- 5 Over 10 years
- 6 *Don't know*

[20] What is [name's] current diagnosis?

[21] How certain are you of this diagnosis?

- 1 Very uncertain
- 2 Somewhat uncertain
- 3 Somewhat certain
- 4 Very certain

[22] Has [name] received other psychiatric diagnoses?

- 1 Yes
- 2 No
- 3 *Don't know*

[23] If yes, what?

[24] How old was [name] when you or your family first decided something was wrong?

- [25] At what age was treatment first sought for [name]?
- [26] At what age was [name] diagnosed with a mental illness?
- [27] Did you live in the same household as [name] when his/her illness began?
- 1 Yes
 - 2 No
- [28] Before the illness began, how many years did you live in the same household as [name]?
- [29] After the illness began, how many years did you live in the same household as [name]?
- [30] Did you and [name] ever share a room together?
- 1 Yes
 - 2 No
- [31] If yes, for how many years?
- 1 Less than 1 year
 - 2 1 - 2 years
 - 3 3 - 4 years
 - 4 5 - 6 years
 - 5 7 or more years
- [32] How many times has [name] been hospitalized for psychiatric treatment?
- 1 Never been hospitalized
 - 2 1 - 2 times
 - 3 3 - 5 times
 - 4 6 - 10 times
 - 5 Over 10 times
 - 6 *Don't know*
- [33] At what age was [name] first hospitalized for psychiatric treatment?
- [34] When was [name] last admitted to a hospital for psychiatric treatment?
- 1 Not applicable (never hospitalized)
 - 2 Is presently hospitalized
 - 3 Within the last six months
 - 4 6 - 12 months ago
 - 5 1 - 2 years ago
 - 6 3 - 5 years ago
 - 7 Over 5 years ago
 - 8 *Don't know*

[35] Where does [name] currently live?

- 01 Parents home
- 02 Your home
- 03 Other family member's home
- 04 Own home or apartment
- 05 Group home
- 06 State Hospital
- 07 Nursing home
- 08 County care facility
- 09 Streets/homeless shelter
- 10 Jail or prison
- 11 Other (specify)

[36] Has [name] ever been homeless?

- 1 Yes
- 2 No
- 3 Don't know

[37] If yes, how many months?

[38] How many miles do you live from [name]?

[39] How often do you see [name]?

- 1 Almost every day
- 2 At least once a week
- 3 2 - 3 days each month
- 4 1 day each month
- 5 Less than 1 day each month
- 6 Not at all in the past 6 months
- 7 Other (specify)

[40] How often do you talk to [name] on the phone?

- 1 Almost every day
- 2 At least once a week
- 3 2 - 3 days each month
- 4 1 day each month
- 5 Less than 1 day each month
- 6 Not at all in the past 6 months
- 7 Other (specify)

[41] How involved are you in the day to day care of [name]?

- 1 Very uninvolved
- 2 Somewhat uninvolved
- 3 Somewhat involved
- 4 Very involved

IMPACT ON ROLES AND RELATIONSHIPS

Now I'm going to ask you what impact [name's] illness has had on specific areas of your life. First I will ask you whether or not [name's] illness has had an impact on a certain area of your life. Then if it has, whether that impact has been mostly positive or negative.

Please answer in the following manner.

Has [name's] illness had an impact on your...

[42] relationship with your parents?

If so, has that impact been mostly positive or negative?

- 1 Very positive
- 2 Somewhat positive
- 3 None / neither positive nor negative
- 4 Somewhat negative, or
- 5 Very negative

Has [name's] illness had an impact on your...

[43] relationship with [name]?

[44] relationship with your other brothers and sisters?

[45] relationship with your spouse?

[46] relationship with your children?

[47] relationship with your friends?

[48] performance at school?

[49] performance at work?

[50] financial resources?

[51] interests and/or recreational activities?

ROSENBERG SELF-ESTEEM SCALE

Next I'm going to ask you some questions about how you think about yourself. For each statement, please tell me if you...

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree

[52] On the whole, I am satisfied with myself. Do you...

- 1 Strongly agree
- 2 Agree
- 3 Disagree, or
- 4 Strongly disagree

with this statement?

[53] At times I think I am no good at all.

[54] I feel that I have a number of good qualities.

[55] I am able to do things as well as most other people.

[56] I feel I do not have much to be proud of.

[57] I certainly feel useless at times.

[58] I feel that I'm a person of worth.

[59] I wish I could have more respect for myself.

[60] All in all, I am inclined to think that I am a failure.

[61] I take a positive attitude toward myself.

SOCIAL PROVISIONS SCALE

In this next part, I am going to give you statements about your relationships with other people. For each statement, please tell me if you...

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree

[62] There are people I can depend on to help me if I really need it. Do you...

- 1 Strongly agree
- 2 Agree
- 3 Disagree, or
- 4 Strongly disagree

with this statement?

[63] I have close relationships that provide me with a sense of emotional security and well-being.

[64] I have relationships where my competence and skills are recognized.

[65] There is no one who shares my interests and concerns.

[66] There is a trustworthy person I could turn to for advice if I were having problems.

IMPACT ON SELF - CONCEPT

Next, I am interested in knowing how your feelings have been affected as a result of [name's] illness. I'm going to read some statements about the ways you may feel. For each statement, please tell me if you...

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree

Since [name] became ill...

[67] I view myself more negatively. Do you...

- 1 Strongly agree
- 2 Agree
- 3 Disagree, or
- 4 Strongly disagree

with this statement?

[68] I feel that I am a stronger person as a result of having been through [name's] illness.

[69] I am afraid that I may become mentally ill.

[70] I feel that I do not have much to be proud of.

[71] I feel that my problem-solving skills are better than average as a result of coping with [name's] illness.

[72] I am more inclined to think that I am a failure.

[73] I feel that I have grown from the experience of having a mentally ill sibling.

[74] I work hard to prove to others that I'm not ill like [name].

[75] I feel that I am more of a person of worth.

EMOTIONAL CLOSENESS

These next statements are about your relationship to [name] growing up and prior to [name's] illness. Again, please respond with...

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree

[76] As children, I felt very close to [name]. Do you...

- 1 Strongly agree
- 2 Agree
- 3 Disagree, or
- 4 Strongly disagree

with this statement?

[77] As children, [name] and I often confided in or shared secrets with each other.

[78] As children, [name] and I spent a lot of time together.

[79] During the two years prior to [name's] illness, I felt very close to [name].

[80] During the two years prior to [name's] illness, [name] and I often confided in or shared secrets with each other.

[81] During the two years prior to [name's] illness, [name] and I spent a lot of time together.

SUBJECTIVE BURDEN

Often families have difficulty dealing with disturbing behaviors of the ill family member. Please indicate the degree to which the following behaviors of [name] have been a problem to the family. Please respond with either...

- 0 *Don't know*
- 1 Not a problem
- 2 Somewhat disturbing
- 3 Very disturbing

[82] Disruption of household routine. Would you say that is...

- 0 *Don't know*
- 1 Not a problem
- 2 Somewhat disturbing
- 3 Very disturbing

[83] Nonsensical communication.

[84] Verbal abuse of others.

[85] Unpredictable embarrassing behaviors in public.

[86] Physical abuse/aggression.

[87] Property damage.

[88] Nuisance to neighbors.

[89] Suicidal threats/attempts.

[90] Drugs/alcohol abuse.

[91] Stealing.

[92] Poor handling of money.

[93] Offensive personal hygiene/grooming.

[94] Unusual sleeping patterns/staying up all night.

[95] Mood swings.

[96] Refusal to take medication.

[97] Side effects of medication (e.g., pacing, sedation).

[98] Lack of motivation.

[99] Social isolation.

[100] Refusal or inability to acknowledge illness.

PERCEIVED SEVERITY

In this next part I am going to ask you some questions about how severe [name's] illness is.

[101] How severe is [name's] illness? Would you say...

- 1 Not at all severe
- 2 Slightly severe
- 3 Moderately severe
- 4 Quite severe
- 5 Extremely severe

[102] To what extent has [name's] illness disrupted his/her own life? Would you say...

- 1 Not at all
- 2 Slightly
- 3 Moderately
- 4 Quite a bit
- 5 Very much

[103] How likely is it that [name's] condition will improve significantly? Would you say...

- 1 Very unlikely
- 2 Somewhat unlikely
- 3 Somewhat likely
- 4 Very likely

[104] How likely is it that there will be a cure for [name's] illness in your lifetime? Would you say...

- 1 Very unlikely
- 2 Somewhat unlikely
- 3 Somewhat likely
- 4 Very likely

DEPRESSION

Now I'm going to read a list of ways you might feel or behave. Please tell me how often you have felt each of these ways during the past week. Please respond to each statement with either ...

- 1 rarely or none of the time
- 2 some of the time
- 3 much of the time
- 4 most of the time

[105] I was bothered by things that don't usually bother me. Would you say...

- 1 rarely or none of the time
- 2 some of the time
- 3 much of the time
- 4 most of the time

[106] I did not feel like eating. My appetite was poor.

[107] I felt that I could not shake off the blues even with help from my family and friends.

[108] I felt that I was just as good as other people.

[109] I had trouble keeping my mind on what I was doing.

[110] I felt depressed.

[111] I felt that everything I did was an effort.

[112] I felt hopeful about the future.

[113] I thought my life had been a failure.

[114] I felt fearful.

[115] My sleep was restless.

[116] I was happy.

[117] It seemed that I talked less than usual.

[118] I felt lonely.

[119] People were unfriendly.

[120] I enjoyed life.

[121] I had crying spells.

[122] I felt sad.

[123] I felt that people disliked me.

[124] I could not get going.

CONTROLLABILITY OF CONSEQUENCES

In this next part, I would like you to think about the types of problems having a sibling with a mental illness presents. Pick a difficult or recent problem you have faced with regards to [name's] illness. What is the problem you are thinking about?

[125] _____

[126] How long ago did this problem occur?

Please answer the following questions when thinking about [problem].

[127] How much control did you have over the consequences of the situation? Would you say you had...

- 1 no control
- 2 slight control
- 3 moderate control
- 4 quite a bit of control
- 5 very much control

[128] How much control did [name] have over the consequences of the situation?
Same response category as question 127

[129] How much control did others (not including [name]) have over the consequences of the situation?
Same response category as question 127

[130] How much could you control the outcome of this situation? Would you say...

- 1 not at all
- 2 slightly
- 3 moderately
- 4 quite a bit
- 5 very much

[131] How much could [name] control the outcome of this situation?
Same response category as question 130

[132] How much could others (not including [name]) control the outcome of this situation?
Same response category as question 130

[133] To what extent were there things you could say or do to alter the situation?
Same response category as question 130

[134] To what extent were there things [name] could say or do to alter the situation?
Same response category as question 130

[135] To what extent were there things others (not including [name]) could say or do to alter the situation?
Same response category as question 130

COPING

Still thinking about this difficult problem, I would like you to indicate what you did and felt when you were experiencing this difficulty.

Then respond to each of the following statements by saying the answer that best describes what you did and felt. Your choices are:

- 1 I didn't do this at all
- 2 I did this a little bit
- 3 I did this a medium amount
- 4 I did this a lot

- [136] I sought God's help.
- [137] I took additional action to try to get rid of the problem.
- [138] I refused to believe that it had happened.
- [139] I tried to come up with a strategy about what to do.
- [140] I looked for something good in what was happening.
- [141] I asked people who had similar experiences what they did.
- [142] I forced myself to wait for the right time to do something.
- [143] I talked to someone about how I felt.
- [144] I learned to live with it.
- [145] I put aside other activities in order to concentrate on this.

LIFE EVENTS

Now I'm going to read you a list important changes that sometimes occur in people's lives. Please indicate whether or not you have experienced each event during the past year. I am only interested in the events that did not involve [name].
During the past 12 months, did you...

- [146] have a close friend move away?
- [147] have a close friend injured or seriously ill?
- [148] have a close friend with serious marital or family problems?
- [149] have a close friend who died?
- [150] take on direct care of an ill or disabled parent or other relative?
- [151] place a parent or spouse's parent in an institution or nursing home?
- [152] have a relative or in-law with serious marital or family problems?
- [153] have an engagement broken?
- [154] have marital problems?
- [155] have marital separation or divorce?
- [156] have your spouse die?
- [157] have a serious illness or injury?
- [158] have a family member with a serious illness or injury?
- [159] have a family member die?
- [160] have an adult child who had problems achieving independence?
- [161] get involved in a lawsuit or court case?
- [162] get robbed?
- [163] get beaten up, physically attacked, or sexually assaulted?
- [164] have an automobile accident in which someone was injured?
- [165] suffer injury or property damage from a fire, severe weather, or other disaster?
- [166] lost your driver's license?
- [167] have difficulties with your boss?
- [168] laid off or fired from your job?
- [169] suffered a serious financial loss not related to your job?
- [170] have some other terrifying or shocking experience?

OPEN-ENDED QUESTIONS

1. What has been the hardest part of having a sibling with a chronic mental illness?
2. Tell me a little about how you have dealt with having a sibling with a chronic mental illness.
3. What has been the most helpful in coping with having a mentally ill sibling?
4. What has been the least helpful?
5. What advice would you give to someone who's brother or sister has just been diagnosed with a chronic mental illness?
6. How has your relationship with [name] changed since the onset of the illness?
7. How has having a sibling with a chronic mental illness affected you own self-image?

APPENDIX D
CORROBORATOR QUESTIONNAIRE

CORROBORATING INFORMATION

ID: _____

[1] *Source:*

- 1 *Mother*
- 2 *Father*
- 3 *Brother*
- 4 *Sister*
- 5 *Other*

I am going to ask you some brief questions about [name].

[2] What is his/her age?

[3] What is [name's] current diagnosis?

[4] How certain are you of this diagnosis?

- 1 Very uncertain
- 2 Somewhat uncertain
- 3 Somewhat certain
- 4 Very certain

[5] Is [name] currently receiving disability for his/her mental illness?

- 1 Yes
- 2 No
- 3 Don't know

[6] If yes, for how many years has [name] received disability?

- 1 0 - 1 years
- 2 1 - 2 years
- 3 3 - 4 years
- 4 5 - 10 years
- 5 Over 10 years
- 6 *Don't know*

[7] How old was [name] when you or your family first decided something was wrong?

[8] At what age was treatment first sought for [name]?

[9] At what age was [name] diagnosed with a mental illness?

[10] How many times has [name] been hospitalized for psychiatric treatment?

- 1 Never been hospitalized
- 2 1 - 2 times
- 3 3 - 5 times
- 4 6 - 10 times
- 5 Over 10 times
- 6 *Don't know*

[11] At what age was [name] first hospitalized for psychiatric treatment?

[12] When was [name] last admitted to a hospital for psychiatric treatment?

- 1 Not applicable (never hospitalized)
- 2 Is presently hospitalized
- 3 Within the last six months
- 4 6 - 12 months ago
- 5 1 - 2 years ago
- 6 3 - 5 years ago
- 7 Over 5 years ago
- 8 Don't know

[13] Where does [name] currently live?

- 01 Parents home
- 02 Study sibling's home
- 03 Other family member's home
- 04 Own home or apartment
- 05 Group home
- 06 State Hospital
- 07 Nursing home
- 08 County care facility
- 09 Streets/homeless shelter
- 10 Jail or prison
- 11 Other (specify)

[14] Has [name] ever been homeless?

- 1 Yes
- 2 No
- 3 Don't know

[15] If yes, how many months?

Now I'm going to ask you some questions about the relationship between [name] and [subject].

[16] Did [name] and [subject] ever share a room together?

- 1 Yes
- 2 No

[17] If yes, for how many years?

- 1 Less than 1 year
- 2 1 - 2 years
- 3 3 - 4 years
- 4 5 - 6 years
- 5 7 or more years

Please answer the following questions with...

- 1 Strongly agree
- 2 Agree
- 3 Disagree
- 4 Strongly disagree

- [18] As children, [name] and [subject] often confided in or shared secrets with each other.
- [19] As children, [name] and [subject] spent a lot of time together.

APPENDIX E
RESPONSES TO OPEN-ENDED QUESTIONS

Participants in this study were asked seven open-ended questions in an attempt to gain more qualitative information regarding the impact of having a sibling with a chronic mental illness. The responses to these seven questions and the implications of these responses are discussed below.

The first questions asked, "What has been the hardest part of having a sibling with a chronic mental illness? The responses to these questions are shown in Table 12. The most common response (15%) referred to the illness having a negative impact on other family members. An additional 14% reported the illness having a negative impact on the relationship with the ill sibling. Eleven percent reported a lack of knowledge of the illness as the most difficult aspect of sibling mental illness. Despite reports in the literature of dissatisfaction with the mental health services and professionals, only three percent reported this as the most difficult aspect.

The second question was, "Tell me a little about how you have dealt with having a sibling with a chronic mental illness." As shown in Table 13, 30% reported that they dealt with it by distancing themselves from the ill sibling. On the other hand, 23% reported that providing support to the ill sibling was how they best dealt with the illness. Learning to accept the illness seemed to be important (12%). Gaining education was a common response (9%). Seeking social support (4%), having a strong faith in God (4%), and having patience (4%) began to emerge as important ways to cope with sibling mental illness.

Responses to the third question were similar to the second (Table 14). The question was, "What has been the most helpful in coping with having a mentally ill sibling?" Thirty-three percent reported that having good social support was the most helpful thing in coping with this stress. Again, becoming more educated was a frequent response (19%). Fourteen percent reported that distancing themselves was the best way to cope with it. Faith in God (11%), learning to accept the illness (9%), and maintaining hope (3%) were mentioned here as well.

Table 12. Responses to "What Has Been the Hardest Part of Having a Sibling With a Chronic Mental Illness?" (N = 79)^a

Response	N	%
Negative impact on other members of the family	12	15
Negative impact on relationships with the ill sibling	11	14
Feelings of helplessness in dealing with the ill sibling	10	13
Lack of knowledge or experience with mental illness	9	11
Accepting the illness	7	9
Seeing changes in the personality of the ill sibling	6	8
Awareness of the inabilities of the ill sibling	5	6
Difficulties communicating with the ill sibling	4	5
Feelings of guilt and embarrassment	4	5
Worries and fears related to the mental illness	4	5
Feelings of grief and loss for the sibling they once knew	2	3
Understanding the bizarre thoughts and behaviors	2	3
Working with the mental health services/professionals	2	3
Feeling burdened by the ill sibling	1	1

^a Some participants gave more than one response; some gave no responses.

Table 13. Responses to "Tell Me a Little About How You Have Dealt With Having a Sibling With a Chronic Mental Illness." (N = 77)^a

Response	N	%
Distanced myself from the ill sibling	23	30
Provided support to the ill sibling	18	23
Learned to accept the illness	9	12
Learned more about mental illness	7	9
Had a very strong emotional reaction (e.g., fear, sadness)	4	5
Faith in God	3	4
Sought out social support	3	4
Learned to take things one day at a time	3	4
Took on more responsibility for the ill sibling	2	3
Tried not to blame the ill sibling or other family members	2	3
Became closer to the other family members	1	1
Exercised	1	1
Took time out to think about the situation	1	1

^a Some participants gave more than one response; some gave no responses.

Table 14. Responses to "What Has Been the Most Helpful in Coping With Having a Mentally Ill Sibling?" (N = 70) ^a

Response	N	%
Leaning on family and friends for support	23	33
Becoming more educated about the illness	13	19
Distancing myself from the ill sibling	10	14
Faith in God	8	11
Learning to accept the illness	6	9
Getting good care and treatment for the ill sibling	4	6
Communicating with the ill sibling	3	4
Maintaining hope	2	3
Exercise	1	1

^a Some participants gave more than one response; some gave no responses.

The fourth question asked, "What has been the least helpful in coping with having a mentally ill sibling?" The responses to this question are shown in Table 15. In response to this question, 33% said there was nothing that was least helpful. Thirty-eight percent reported that some person interfered with their ability to cope with having a mentally ill sibling; 18% reported other family members, 10% reported the ill sibling, and 10% reported other non-relatives. Also, 8% reported difficulties with the mental health services and/or professionals. Lack of knowledge was also an important factor (6%).

The fifth question was, "What advice would you give someone who's brother or sister has just been diagnosed with a chronic mental illness?" As shown in Table 16, the most frequent response was to stick with the ill sibling; don't abandon him or her (21%). Education

Table 15. Responses to "What Has Been the Least Helpful in Coping With Having a Mentally Ill Sibling?" (N = 49) ^a

Response	N	%
Nothing	16	33
Other family members	9	18
Feelings of helplessness	5	10
Other people	5	10
The mentally ill sibling	5	10
Mental health services and/or professionals	4	8
Lack of knowledge and experience with mental illness	3	6
Financial strain	2	4

^a Some participants gave more than one response; some gave no responses.

Table 16. Responses to "What Advice Would You Give Someone Who's Brother or Sister Has Just Been Diagnosed With a Chronic Mental Illness?" (N = 90) ^a

Response	N	%
Be there for the ill sibling/ Don't abandon the ill sibling	19	21
Become educated about the mental illness	17	19
Don't let the illness interfere with your own life	17	19
Have patience/ Don't give up hope	15	17
Get support for yourself	13	14
Have faith in God	5	6
Be an advocate for the ill sibling	4	4

^a Some participants gave more than one response; some gave no responses.

about the illness was again a popular response (19%). A large number (19%) also said to be sure that the illness does not interfere with your own life. Maintaining hope (17%), seeking support for yourself (14%), and faith in God (6%) were also common responses.

The next question focused on how the relationship between the participant and the ill sibling had changed since the onset of the illness. The responses to question six are shown in Table 17. Thirty-six percent of the responses related to growing closer since the onset of the illness; 15% reported grown further apart. Some participants (21%) reported the ill sibling had become a totally different person since becoming ill. Fourteen percent reported becoming more of a caregiver than a sibling. Surprisingly, 10% reported no change in the relationship since the onset of the illness.

The final question asked, "How has having a sibling with a chronic mental illness affected your own self-image?" As shown in Table 18, 50% reported that having a sibling with a chronic mental illness did not affect their self-image. Seventeen percent reported that having a sibling with a mental illness strengthened their self-image; 12% reported it lowered their self-image. Twelve percent reported having fears of their own mental health. Nine percent reported that they had become more appreciative of their own mental health as a result of having a sibling with a mental illness.

It appears that, despite the difficulties involved with having a sibling with a chronic mental illness, many of the participants in this study reported adjusting relatively well to the stress. There were several common themes in these open-ended question responses. First, it is apparent that there are negative consequences involved with having a sibling with a chronic mental illness. These include emotional reactions, family difficulties, and changes in the relationships with the ill sibling. Second, the mentally ill sibling is often viewed as making matters more difficult. Many of the participants reported needing to distance themselves from the ill sibling in order to be better able to deal with having a sibling with a mental illness. However, many respondents also reported feeling closer to the ill sibling since the onset of the illness. Third, other people play an important role in how well individuals cope with sibling mental illness. Social support seemed to be a very important factor. Interestingly, it was reported that family members could be as hurtful as they are helpful. Surprisingly, there were

few complaints about the mental health services and/or professionals. Maybe people the mental health field have heard the complaints and have begun to respond appropriately. Fourth, education about mental illness seems to play an important role in how well individuals adjust to sibling mental illness. This theme was shown in responses to several questions. Fifth, having faith in God and/or being able to maintain hope were important factors. Sixth, sibling mental illness may not have a strong impact on well sibling self-concept. Half of the respondents reported no impact. In addition, if there is an impact, it may as likely be a positive one than a negative one.

Table 17. Responses to "How Has Your Relationship With Your Ill Sibling Changed Since the Onset of the Illness?" (N = 73)^a

Response	N	%
We've grown closer	26	36
The ill sibling has become a totally different person	15	21
We've grown further apart	11	15
Become more of a caregiver	10	14
No change	7	10
Much more cautious around the ill sibling	4	5

^a Some participants gave more than one response; some gave no responses.

Table 18. Responses to "How Has Having a Sibling With a Chronic Mental Illness Affected Your Own Self-Image?" (N = 58) ^a

Response	N	%
It hasn't	29	50
Strengthened my self-image	10	17
Have fears of own mental health	7	12
Lowered my self-image	7	12
More appreciative of my mental health	5	9

^a Some participants gave more than one response; some gave no responses.

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